



# The Company We Keep:

A user's guide to mental health clinicians

**PSYCHIATRISTS, GPs,  
PSYCHOTHERAPIST, I  
CASE MANAGERS, NUR  
PSYCHOLOGISTS, SUP  
COUNSELLORS, PHYSIC  
OCCUPATIONAL THERAP  
PSYCH NURSE, KEY WORK  
CONSULTANT, STUDENT O  
REHABILITATION COUNS  
TWO HATS, CHARGE NUR  
SUPPORT WORKER, PSY  
NURSES, ALLIED HEA  
SOCIAL WORKER, S  
COUNSELLING**



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# The Company We Keep

A user's guide to mental health clinicians

This is the fifth in a series of publications written by and for mental health consumers by Our Consumer Place, a groundbreaking mental health resource centre run by people with a diagnosis of 'mental illness' (consumers). Our Consumer Place ([www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au)) is funded by the Department of Health (Government of Victoria) and auspiced by Our Community ([www.ourcommunity.com.au](http://www.ourcommunity.com.au)). We offer information and advice to individuals and groups who are providing or thinking about providing consumer developed initiatives.

### **The Company We Keep: A user's guide to mental health clinicians**

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### **The Company We Keep: A user's guide to mental health clinicians**

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Cartoons by Merinda Epstein ([www.takver.com/epstein/](http://www.takver.com/epstein/))

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## Foreword

This publication is the fifth in a series of consumer-developed publications produced by Our Consumer Place ([www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au)), a groundbreaking mental health resource centre run by people who have been diagnosed with 'mental illness' (we call ourselves 'consumers').

Funded by the Department of Health (Government of Victoria) and auspiced by Our Community, Our Consumer Place offers information and advice on consumer perspective and consumer leadership for individual consumers, groups of consumers and anyone else who is supportive of this orientation.

Most of the available information on mental health has been written by other sorts of 'experts' – mental health professionals, mental health charities, or researchers who are not consumers. Our booklets are different – they are written by people who have been labelled with 'mental illness,' based on our knowledge, and drawn from our lived experiences.

This publication provides an overview of some of the important information consumers tell us they would love to have known 'from the beginning'. In some places reference is made to our website, where readers can find more detailed information about something that is particularly technical or where we have used narrative skills to produce material that can be downloaded and used illustratively.

We hope to follow this publication with another on services.

### A note on language

Throughout this publication, you will notice we have used the term 'consumer' to describe what's more commonly referred to as "a person with a mental illness". No word is perfect, not all of us know instantly (and identically) what a certain word means, not all of us will identify with the same term and lots of us dislike certain words. Our Consumer Place tends to use the word 'consumer', which is more common in Australia than other terms and is probably the best we have for now. There are more thoughts about this issue on our website ([www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au)).

You may also notice that in this publication (as other Our Consumer Place publications) we put many words (e.g. 'mental illness'; 'patient'; 'sickness') into inverted commas. People tend to use these words because they are commonly understood in the mental health field, but by putting them in inverted commas we are acknowledging that not everyone agrees with their use – these terms are contested. For example, the idea of 'mental illness' is not something that all consumers identify with – many reject it, often with sophisticated intellectual, political or spiritual critiques of this concept. Others find the term profoundly useful. Again, there is more discussion about this topic on our website.

This is a booklet about clinicians. Many readers will be surprised to see that we use this word inclusively. Here clinicians include: GPs, mental health nurses, occupational therapists, clinical psychologists, counselling psychologists, counsellors, social workers

and psychiatrists. In other discourses the word clinician refers only to medical doctors. We prefer to treat everyone with the same respect of title, reflecting the ideology not only of consumers but also of Victorian Mental Health Policy, which sanctions the importance of functional multidisciplinary teams.

### **A note on sub-headings**

During 2012 Our Consumer Place ran a competition inviting consumers to send in definitions for common events, people, places and ideas in mental health with a twist of black humour; punning, slapstick and plain good fun. More than 1500 entries were received, edited down to 250 by Indigo Daya, Coordinator of Voices Vic: The Hearing Voices Network of Victoria. The collection, dubbed the MadQuarry Dictionary 2013, is available from the Our Consumer Place website – [www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au).

### **A note on complexity**

The Australian medical and mental health systems are incredibly complex.

While we have tried in good faith to provide a path through the maze, we acknowledge that some sections may appear over-simplified or may have become out of date.

We urge readers to use this booklet as a guide to aid their own research, rather than the final word.

### **Dedication & acknowledgements**

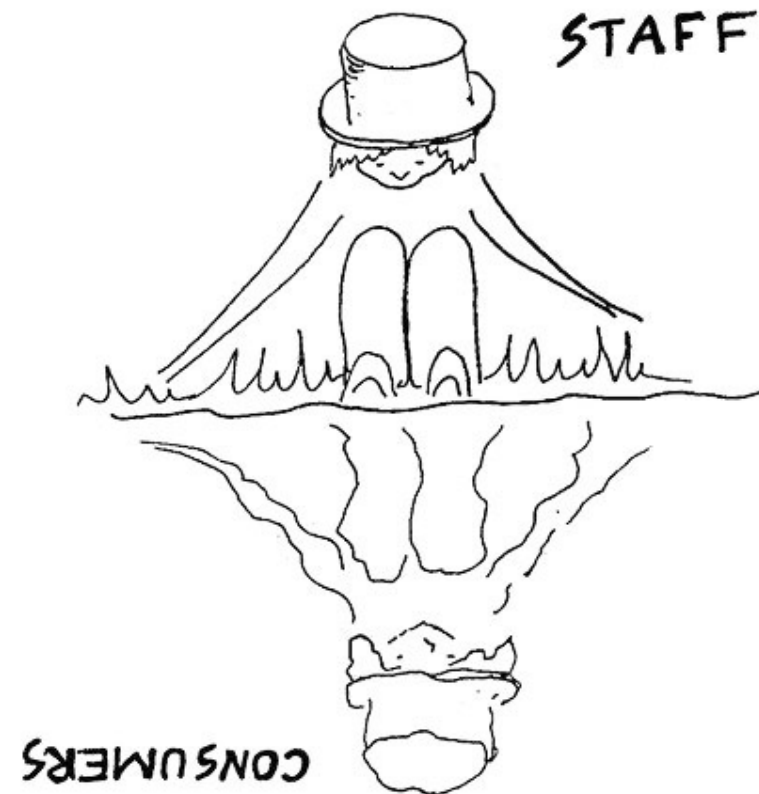
Ann Tullgren worked on this booklet in the middle stages of its evolution. Her help and guidance is gratefully acknowledged.

Thanks too to Sara Clarke for her contribution to the booklet and for Deb Martinson for allowing us to use her material.

Thanks also to the Department of Health (Government of Victoria) and Our Community for providing the funding and the support that allows Our Consumer Place to exist.

Merinda Epstein  
Our Consumer Place  
[www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au)

# **SECTION I: Introduction**

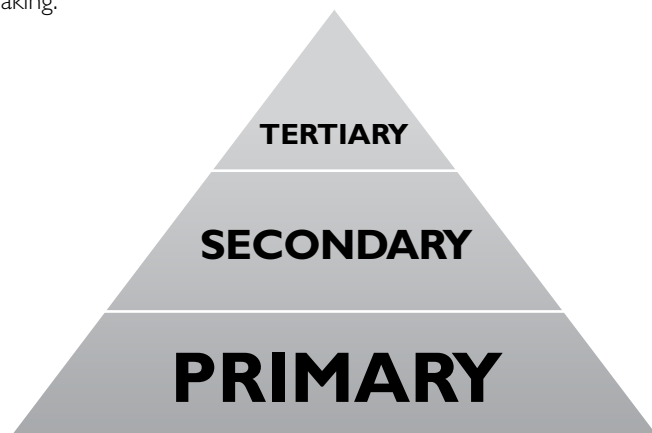


## \* Primary, Secondary and Tertiary Clinicians

**Saving face: verb** Being seen to be professional is primary.  
Saying sorry is secondary.

*2013 MadQuarry Dictionary entry*

Knowledge is power. Sometimes powerful knowledge can seem academic or less relevant than some of the more practical forms of knowing and doing. Understanding the health clinician's own ways of organising their knowledge and their work is fundamental for those of us who want more power over our own lives and health decision making.



### Primary care

The term 'primary care' refers to the first and most general layer of the health system. It's the first stop, where we go for generalised, perhaps less severe, experiences of what doctors call 'symptoms'.

The primary care clinicians we most commonly encounter will be general practitioners (GPs), though if we attend a Community Health Centre rather than a private GP practice, it may be a nurse practitioner or counsellor that we see.

There are also a small number of primary care specialists, such as GPs trained as counsellors, who run counselling practices subsidised by Medicare. These are likely to increase as people start to recognise the special skills and attributes that are necessary for providing good-quality primary care.

As consumers we are aware of the influence of the uneven distribution of power across the health system. GPs are generally less well remunerated and can be considered lower status than some other doctors. This is despite the fact that often these are the clinicians with whom we can communicate best.

GPs often have a tough time with mental health, having to deal with crisis teams that are sometimes reluctant to respond, and often failing to find any service at all for

very distressed consumers. Many consumers report that their GPs have fought really hard for them but given up.

Primary care clinicians tend to treat acute problems; in a mental health context this could be anything, even including losing our medications when missing even a day is crucial.

They have a large role in 'managing' chronic 'mental illness', including those of us with 'high prevalence' mental illness (anxiety and depression mainly) and those who are refused entry into public services.

Primary care clinicians are also generally responsible for co-ordinating all the medical services (both physical and mental) that we use. This requires a high level of doctor-to-doctor communication, which is not always forthcoming.

### Secondary care

After first being seen in a primary care setting, some of us may be referred to specialists – this is part of secondary care.

Put simply, secondary care providers are people with greater expertise in a much more limited medical sphere. Specialists focus either on a specific body system or on a specific disease or condition. For example, cardiologists focus on the heart, endocrinologists focus on our hormones, oncologists work on cancers, and psychiatrists deal with mental 'illness'.

Some of us have multiple specialists in our lives, either relating to our mental health diagnosis, or not.

It's difficult to go directly to secondary care as you usually need a referral from a primary care clinician (usually your GP) before you can access Medicare benefits for a visit to a specialist. Some referrals only last a year, but we may get an ongoing referral if it's considered that we are likely to need long-term care from a secondary care clinician.

While we may end up seeing the secondary clinician (or specialist) more frequently than the primary care provider, they do not take over responsibility for our primary care. That role, sometimes a bit ambiguously in psychiatry, remains with the GP.

### Tertiary care

It's rare to come into contact with this aspect of the mental health system without first going through primary and secondary care consultations. In fact, tertiary care often happens after we have been hospitalised and it's felt that there is a need for super-specialised knowledge and equipment.

In such cases, our surgeon or physician might ask that we be seen by a specialist in a very specific area. Tertiary care specialists may have a very narrow knowledge base but within this highly specialised area, there isn't much they don't know (if they don't they will generally call on tertiary specialists interstate or overseas).

Tertiary care requires highly specialised equipment and expertise; examples would include coronary artery bypass surgery, renal or haemodialysis, some plastic surgeries



or neurosurgeries, severe burn treatments or any other very complex treatments or procedures.

The psychiatric equivalent would be the super-specialist who admits patients into private hospitals to explore polypharmaceutical responses to a range of new and emerging medications to try and 'help' someone who is not responding to any other medical drug 'treatments'.

This might also happen in the public sector, particularly in the area of psychosis, as some psychiatrists stay working in perhaps this less lucrative public end of psychiatry because it gives them the flexibility and support to follow research in which they have an interest.

## \* Accreditation & Registration

**Power: noun** The more you have the less effort it takes to make or maintain social institutions that suit you

*2013 MadQuarry Dictionary entry*

The Australian Health Practitioner Regulation Agency (AHPRA – <http://www.ahpra.gov.au/>) is the organisation responsible for the implementation of the National Registration and Accreditation Scheme across Australia.

AHPRA supports the 10 National Health Practitioner Boards that regulate clinicians – not all of whom work in mental health. They cover the professions of chiropractors, dentists, medical, nursing and midwifery professionals, optometrists, osteopaths, pharmacists, physiotherapists, podiatrists, and psychologists. (Note that it does not include social workers.)

The Boards (e.g. the Nursing and Midwifery Board of Australia, the Medical Board of Australia, the Psychology Board of Australia) work to publish and set standards and policies that all registered professionals must meet. Complaints can be made through their member organisations.

Some of the member boards, like the Medical Board of Australia, have branches (such as the Medical Board of Victoria). Complaints will usually be referred to the local Board.

The Boards are responsible for holding the registration details of each practitioner in their field (if registration is required). This information must be made available to the public upon request. Consumers can, perhaps, use this information whilst making decisions about a suitable therapist.

Members of the public may also make a notification (legal jargon for 'complaint') to AHPRA about the conduct, health or performance of a practitioner. See the chapter on 'Making a Complaint' for more on this.

Relevant Boards affiliated with APHRA include:

- **Psychologists**  
Psychology Board of Australia (PBA)  
<http://www.psychologyboard.gov.au/>
- **Nurses**  
Nursing and Midwifery Board of Australia  
<http://www.nursingmidwiferyboard.gov.au/>
- **Nurse Practitioners**  
Australian College of Nurse Practitioners  
<http://www.acnp.org.au/>
- **Medicine**  
Medical Board of Australia  
<http://www.medicalboard.gov.au/>
- **Occupational Therapists**  
Occupational Therapy Board of Australia  
<http://www.ahpra.gov.au/occupational-therapy.aspx>

## Professional bodies

The second tier mechanisms for maintaining standards are the professional bodies that have an interest in making sure their profession is as squeaky clean as possible.

However, these organisations are there primarily to protect the interests of their members so it's important not to assume they will either have the information you need or will give it to you. Their complaints mechanisms may not always work to the benefit of a consumer:

Professional organisations fulfil a range of roles, including:

- Provision of professional indemnity insurance;
- Provision of professional support, resources, journals, and networking;
- Accreditation of university courses;
- Overseeing an occupation-specific code of ethics (including complaints);
- Lobbying and promoting their profession; and
- Competing with other professional bodies for ascendancy in mental health as a clinically specialised area.

Members of the public are often able to find a practitioner through a professional association (note that not all members of any given profession may belong to a professional association).

Below is a list of professional associations, bodies and colleges which might be useful.

- **Psychologists**  
Australian Psychological Society (APS)  
<http://www.psychology.org.au/>

- **Mental Health Nurses**

Australian College of Mental Health Nurses  
<http://www.acmhn.org/>

- **Counsellors**

Australian Counselling Association  
<http://www.theaca.net.au/>

- **Counselling Psychologists**

Australian Psychological Society (APS)  
[www.psychologyboard.gov.au/](http://www.psychologyboard.gov.au/)

- **Psychiatrists**

Royal Australian and New Zealand College of Psychiatry (RANZCP)  
<http://www.ranzcp.org/>

- **General Practitioners**

Royal Australian College of General Practice (RACGP)  
<http://www.racgp.org.au/>

- **Psychotherapists**

Psychotherapists and Counselling Federation of Australia (PACFA)  
<http://www.pacfa.org.au/>

- **Emergency Clinicians**

Australian College of Emergency Medicine  
<http://www.acem.org.au/>

- **Social Workers**

Australian Association of Social Workers (AASW)  
<http://www.aasw.asn.au/>

- **Occupational Therapists**

Australian Association of Occupational Therapists  
<http://www.otaus.com.au/>

- **Family Therapists**

Australian Association of Family Therapy (AIFT)  
<http://www.aaft.asn.au/>

### A consumer perspective

These organisations can provide invaluable information about the professions they support. You can often find private clinicians through them and, if you're lucky, you might be able to speak to someone about the sub-specialties within their discipline; for example, you might be able to talk through the difference between psychotherapy and cognitive behavioural therapy.

Each of these organisations will have glossy pamphlets and promotional material available. All of this is useful but it's important to note that it is also both commercial and political. Whatever their desire, professional associations can never be neutral; they are there to represent their member clinicians, not us.

It's also useful to note that there are turf wars that go on within various clinical spaces; these organisations not only compete with each other but also internally. Sometimes position holders instinctively promote their areas of interest to people seeking guidance in choosing clinicians. This problem is exacerbated by the fact that most of the websites disallow consumers from the more detailed, interesting and useful debates because this material is only available for members.

Under these circumstances the most useful way to go in using the professional bodies to gain information is to take the essence from the pamphlets and then do your own research, or go through consumer organisations (including the written material from Our Consumer Place).

### \* Clinicians in Different Settings

**Workcover Retiring: verb** By the end of it you end up surrendering painfully and the 70-year-old Workcover psychiatrist ends up retiring gratefully.

*2013 MadQuarry Dictionary entry*

Mental health-trained clinicians are found all over the place.

It's impossible to outline all the many settings in which we might encounter them but we have chosen a small set of common places to underline.

It is important to remember that different professional groups train in different ways. For example, a psychiatrist has done six years of undergraduate study and then five years of post-graduate study to become a specialist in mental health.

Although the year blocks are different, a mental health nurse's trajectory is a similar one. Once graduated, a psychiatric nurse is a specialist in mental health nursing.

On the other side of the coin are occupational therapists and social workers who graduate as generalists and who specialise 'on the job' and through their professional organisations.

This determines, to some extent, the territory range of the different professional groups roaming medical and social policy and organisations.

### Centrelink

Many people living with 'mental illness' exist (often with great difficulty) on a Disability Support Pension (though there are moves from time to time to move people on such pensions onto other types of welfare or indeed into or back to work).

Centrelink is not a happy place for many consumers. We often encounter professionals (such as 'case managers') on the front line who are using the language



of control and punishment, talking about 'managing people', 'supervising' us and calling us 'cases'. Relationships are often fraught regardless of the clinical background of the worker.

Probably some of these workers were born to be bossy, but no doubt many find it unpleasant to work in a manner and context that contradicts their beliefs and education.

Many consumers need help to navigate the system. When it's forthcoming it is often from a social worker.

## Housing and employment workers

Many social workers, mental health nurses and occupational therapists are employed in positions that are primarily involved with supporting people diagnosed with 'mental illness' to find housing and/or meaningful work. (The true nature of 'meaningful' is debatable!)

We won't necessarily know what sort of training workers in the housing and employment sector have as most of the positions are given generic titles such as 'case worker' or 'case manager' – terms most consumers reject.

These clinicians see themselves as working in a very different and more emancipated way than clinicians in medical settings; however complaints can still be made about their practice through their professional bodies.

There will be more about these positions in our upcoming booklet on services.



## Disaster relief

Mental health trained practitioners are obvious candidates to provide 'case work' after both natural and man-made disasters.

After the Black Saturday bushfires 'case workers' were recruited from all over the place, and the toll on the mental health workforce was significant. Many people with 'case workers' in mental health lost their support as they were called upon to provide help for victims of the terrible fires. These things happen. But it's good to have a basic grasp of the fact that a huge new demand will put pressure on the system and possibly you.

## Asylum seekers

It makes sense that mental health trained clinicians would be working with asylum seekers. At the Asylum Seekers Resource Centre in Melbourne, for example, there are volunteer clinicians working alongside volunteers from the mental health consumer movement. This is a commendable cooperative model.

## Medico-legal settings

The two groups of clinicians we are most likely to cross paths with in the medico-legal field (the place where the legal profession meet the professions of medicine) are psychiatrists and social workers.

Most psychiatrists who work in this area tend to specialise and even to sub-specialise, picking up a workload from large corporations such as the Motor Accident Commission or Workcover.

Others might do specialist work for law firms who are defending people diagnosed with 'mental illness' against the institutions of the state, or matters where psychiatric disability is involved. This may include crimes where a legal argument could be put that a person's disability might in some way mitigate the legal case.

To learn more about this setting, visit the website of the Medico-Legal Society of Victoria: <http://www.mlsv.org.au> or Legal Aid: <http://www.legalaid.vic.gov.au/>.

Social workers may also play a role in the court process. People diagnosed with 'mental illness' might be either the complainant or the defendant in a court matter and in either of these positions social workers can find information, reassure, make sure everyone who should be there is there, inform people of their rights, organise childcare, take children away from their parents or try to find accommodation for a defendant from out of town.

## The Mental Health Court Liaison Service

This liaison service is staffed by many allied health clinicians, including social workers. It is designed to protect people diagnosed with mental illness from some of the combative components of the courtroom.

The Mental Health Court Liaison Service is an initiative of the Magistrates' Court of

Victoria. Specialist witnesses may be called to give learned opinion about many things including a person's 'medical capacity' and/or 'fitness to plead'. These experts are likely to be senior psychiatrists.

See <http://www.courts.vic.gov.au/courts-tribunals/specialist-courts-and-programs>

### **Mental Health Review Board**

For those of us who are periodically held in hospital under the Victorian Mental Health Act, or permanently under a Community Treatment Order, the role of the Mental Health Review Board is enormous. We are beholden to these review panels for our liberty.

The new Victorian Mental Health Act will be legislated very soon. It will change the roles of the most of the players. It's important to keep up to date – see <http://www.health.vic.gov.au/mentalhealth/mhactreform/>

The Mental Health Review Board is made up of three people. The chair must be a lawyer and there must be an independent psychiatrist and a well informed (well informed by whom? we sometimes ask) community member.

The precise people change but the structure of the Review Board is in the legislation – see <http://www.mhrb.vic.gov.au/>

### **Other medico-legal settings**

There are of course many other places where consumers come across mental health trained clinicians in legal proceedings: defamation, failure of duty of care proceedings, negligence, support to regain custody of children removed by child protection, challenging discrimination in employment, and insurance are but a few examples.

In some of these instances clinicians (usually psychiatrists) are testifying for us and in other cases defending themselves against us. It is extremely difficult to engage solicitors from community legal centres if you are not on a Centrelink pension and it's expensive to use the legal system. It's hard to get recommendations but there are some private law firms in Melbourne that have a particular interest in mental health issues.

Some of these, like some psychiatrists, have a sliding scale of fees. Ask around to see if you can find a good one. Try contacting Victorian Legal Aid to recommend a private firm (see <http://www.legalaid.vic.gov.au/>), or get in touch with a community legal centre (<http://www.communitylaw.org.au/>).

### **Mainstream hospitals**

Liaison psychiatry, also known as consultative psychiatry or consultation-liaison psychiatry, is the branch of psychiatry that specialises in the interface between medicine and psychiatry, usually taking place in a hospital or medical setting.

The role of the consultation-liaison psychiatrist is to see patients currently admitted as general medical inpatients at the request of the treating medical or surgical consultant or team. This is known as a 'consult' and constitutes the consultation facet of the role.

As well as the consultation, psychiatrists might be involved in providing treatment during the time we are in hospital, and may also serve a referral role if this deemed necessary.

It's usually an awful shock for people who have never seen any sort of mental health clinician before to suddenly find a psychiatrist at their bedside. For some it is accepted with relief but for others it is shaming, embarrassing and scary. It's something that needs to be handled with great skill because large public hospitals are never the most private of places.

### **Workcover**

Workcover is the scheme that provides compensation for workers who are injured in the course of their employment.

This is an area of concern for consumers. This is partly because it can be very difficult (and indeed terrifying) to confront the edifice of Workcover with a workplace claim that is psychological rather than predominantly physical, but of equal concern are the reports of consumers (in large numbers) that Workcover processes seem to be deliberately designed to discredit them.

Many have described the tone of the initial Workcover psychiatrist interview as being dismissive, judging, rude, unbelieving, full of tricks and counter-tricks, way too short, and arrogant.

Indeed, some have reported that the entire process has been so stressful and distressing as to create its own mental health problems, which can, then, reinforce false accusations.

Fighting decisions made in a short period of time by a clinician we don't know can be exhausting, frequently futile and can seriously affect our health. The best advice from others seems to be to try not to get stuck in the dispute no matter how 'right' you are, and no matter how 'right' you believe your own psychiatrist to be. It's always about weighing up the potential gain against the potential harm.

### **Psychiatric Disability Support Sector (PDSS)**

The Psychiatric Disability Support Sector (PDSS) is the largest growing sector in mental health in Australia at this time.

The services they provide are presently orientated around ideas of community inclusion and recovery'. These are fashionable. They, too, will have their day.

Many clinicians are employed in various roles in this sector, usually as 'case workers', key workers, 'case managers' or service management staff. Sometimes we have to ask to find out what clinical background our key worker might have. Some staff in this sector are TAFE educated.

Clinicians in a PDSS setting are under the same obligations in relation to clinical standards as those working in the clinical sector. And consumers, usually called 'clients' or 'residents', have the same rights to complain about what they experience as unprofessional behaviour as patients anywhere. See the section titled 'Making a Complaint' for more on this topic.

Many people believe that the PDSS sector is totally separate from the clinical sector; however there are many workers from the five core clinical groups (psychiatric nurses, occupational therapists, psychiatrists, psychologists and social workers) working in these settings these days. Clinicians frequently sit on the boards of these large organisations.

PDSS organisations are now providing "step down, step up" services (PARCs – Prevention and Recovery Care Services), which are designed to give people somewhere to go if they're starting to get 'ill' or during those days that we know are treacherous immediately post discharge. PARCS can be seen as the doorway between clinical and community services and the last step, where clinicians are called by their clinical designation – psychiatric nurses, psychologists, occupational therapists and social workers – before these labels morph into 'workers' of various types which are the drones of the PDSS sector (though psychiatrists appear to remain psychiatrists).

## Child protection

There is constantly a dearth of child protection workers in Victoria (most likely because it is a hideous job where there aren't too many happy endings).

As consumers, our experience with the child protection world is most likely to involve a situation where our parenting skills are being called into question, and where assumptions are made, sometimes prejudicially, based on our diagnosis.

In this arena it is social workers who stand on the front line.

This is the most awful of circumstances in which to meet a social worker; a setting where communication is weird, people are angry, terrified and powerless, and where misunderstandings are intensified by issues of social class, gender, age, poverty, ethnicity and race.

Like in so many settings, we often find ourselves dealing either with clinicians who are brand new (the only ones prepared to do this work). With all the gallantry in the world most flail in the impossibility of it all, are frustrated by the red tape and either suffer compassion fatigue or start losing their idealism. It's a breeding ground for cynicism and more experienced campaigners, usually social workers, sometimes forget who they are there for.

Some consumers who have had their families devastated are fighting back. The Family Inclusion Network (<http://www.fin-qldtsv.org.au/>) originated from the idea of a retired social worker and is now spreading around Australia. FIN brings together people who have lost their children to the state, and adults who were relinquished to the state, giving them a way to meet, provide peer support and fight for justice.

## Management

Right through mental health clinical services and the PDSS sector there are clinicians who are working at increasingly senior levels in a managerial way.

As in teaching and some other professions, there is a phenomenon which effectively forces good clinicians to stop doing the work they're good at in order to get promotion and a better salary. This means that we often lose good practitioners to management.

On the other hand, if managers truly do represent our values, rights, needs, communication requirements, safety and so on this might then slowly trickle back into the psych unit.

Really good clinical leaders are a commodity to be nurtured. The combination of being able to efficiently run a service, crack down on inadequate or incompetent staff, be brave, stand up to bosses on an issue of ethical importance, give precedence always to the needs of consumers, and keep a staff team working together in such a fraught area is extremely difficult. Such role models, working alongside consumer role models in partnership, need to be increasingly involved in clinical education.

Unfortunately, however, the criteria used to select people for management sometimes has a lot more to do with 'pushiness', qualifications, knowing how to speak 'proper', dubious definitions of competency, and the word of mouth of staff rather than consumers.

At higher levels in the PDSS sector, managers are increasingly being chosen for their capacity in business, ability to pull in research and development dollars, track records for 'getting things done no matter how', lobbying, and 'sucking up' to politicians. Questions about ethics, empathy, clinical affinity, and tenaciously backing the consumer movement are being squeezed.

## Bureaucracy

It shouldn't be surprising that there are a lot of people trained in the five disciplines that predominate in mental health who are working in the bureaucracy.

Some of the very junior positions are held by graduates who have had almost no experience in their chosen professional arena, while in other cases experienced clinicians have made it all the way up to the highest management levels as outlined above.

As the PDSS sector has grown and become much more influential in policy and the politics of mental health programs at a state level, there has been a rapidly increasing flow of senior clinicians back and forward between the Mental Health, Drugs and Regions Division of the Department of Health, and the large organisations in the community sector such as MIND, Mental Illness Fellowship, Prahran Mission and NEAMI.

## \* Emergency Departments

**Emergency Departments: noun** We need 'slow', they go 'fast'; we need 'room' they have 'no room'; we need 'stabilising' they need 'perpetual movement' of beds; we need 'consistency of personell'; they are at 'full capacity'; we need 'care' they need 'triage'; we need 'understanding' and it's not the right place for understanding; we need to say 'sorry' for taking up their precious time and they can't hear 'sorry' when we've stuffed up their night.

*2013 MadQuarry Dictionary entry*

People diagnosed with 'mental illness' often have encounters with staff from the emergency departments of public hospitals. There are many reasons for this and many of them stem from the demand that is placed on inadequate mental health services and the fact that we often have nowhere else to go.

Other reasons include the 'dumping', by both police and ambulance services, of people who are very distressed because they don't know what else to do. There may be incidents of self-harm or suicide attempts involved.

Unfortunately for some of us, our lives have been so wretched that hospital seems to be the only place of refuge.

Hospital emergency departments are busy places. They are like a giant centrifuge where hundreds of people come through the doors each day and are, as rapidly as possible, assessed and shot out in many directions including: bandaid and then home, the psychiatric Emergency Department Crisis and Assessment Team (E-CATT); intensive care; x-ray; transfer to another facility or up to a medical or surgical ward.

Managing this manic operation is a function of the various clinicians that work in the emergency department setting. Some of them are specialists trained in emergency medicine, some are in training, some are newly qualified doctors (residents), and there are also highly trained nurses (though there may or may not be a psychiatric nurse on duty), as well as students of differing disciplines and experience.

### An important note

Some of the information in this chapter about what may or may not happen in an emergency department may sound off-putting; even terrifying. We so much want every person reading this booklet to stay alive. If you do feel suicidal, and you have somewhere to go that you trust, please go there. If there's something you can do that you know will save your life, then please do it. There is no shame in going to the emergency department, even if you know you will not get the understanding and respect that you deserve (though you never know – you just might!).

If you are treated respectfully and with genuine compassion please let the service

know. They need respect and reinforcement of good behaviour. Obviously, the opposite is also true and there is information elsewhere in this publication on how to make a complaint. The more we make complaints, the more likely it becomes that things will change.

### Attitudes

It is generally fair enough to say that mental health consumers are not well liked in emergency departments.

Clinicians attracted to work in this setting tend to have different sorts of priorities, interests and things that inspire their energy and imagination than what we can provide.

They work fast. They have to. They make big decisions quickly. They are internally and externally focussed on those who they judge might die. Many of them don't know how to diffuse difficult psychological situations, nor have the desire to try.



## Medical versus mental health problems

It's important to note that our mental illness 'red spots' will most likely be all over our medical histories. Regardless of whether we have come in with a broken arm or a hernia they will all know that we are 'a psych. case'. This might or might not influence their behaviour towards us.

Some of us hate this and avoid going to emergency departments at all, even when we are very sick. This is dangerous.

Some of us try to divide up the emergency departments we attend, going to a hospital geographically distant when we are seeking help for medical rather than mental health problems (though obviously we can't do this if an ambulance is involved).

Others still try to utilise an Advance Directive (see later on in this section), though time-pressured emergency department staff are often reluctant to read them.

## Psychosis

Many emergency department clinicians believe that people exhibiting 'scary' (to them, as well as other patients) or 'florid' (the term they use to describe us when our behaviour is very odd) psychotic symptoms should be routed straight into psychiatric services, by-passing casualty services completely.

The lack of education from a consumer perspective is obvious in some emergency department staff. Unfortunately, sometimes restraints are used and certainly security guards may be utilised. The Emergency Crisis, Assessment & Treatment Team (E-CATT) may be called.

If we are upset and angry 'Code Grey' may be boomed over the loud speaker and everyone will come racing into our cubicle to secure the safety of staff even when our anger and distress might be part of our internal experiences of fear and torment and is certainly not deliberate. The experience of having people rushing at you – including security guards – can be terrifying.

It's useful to know some of the medical language that will be being used around us. The word 'incident' is hospital lingo for anything that causes fear or breaches hospital security or is potentially likely to be explosive in an emergency department context.

All of this can, of course, heighten our fear and make things worse. The aim of emergency department staff in such cases will be to get us into a psychiatric unit as quickly as possible. The process of "sectioning" us (locking us up against our will) may be initiated.

## Suicide attempts

Suicide attempts are treated according to the "degree of seriousness", as decreed by emergency department staff.

A collective judgement is made about whether we were really serious or not, also differentiating self-harm from a 'real' suicide attempt. This is actually an artificial

division that leads not so much to differential treatment but certainly to differential attitudes, as revealed in the language used.

If we find ourselves in hospital after a "serious" suicide attempt – a significant overdose, for example – action happens very quickly; our stomach may be pumped, for example.

Note, though, that the emergency department team is there primarily to stabilise our physical health. This might happen in the emergency department itself or, in very serious situations, we might be transferred to the intensive care unit.

Those of us deemed to have made a less serious attempt at self-harm are likely to have a rather different experience in the emergency department. Action is slower and the language used is very different, and often very demeaning. This has an unfortunate effect. It's horrible when we've worked really, really hard to deal with strongly demanding suicide voices, having made great efforts to reduce the physical consequences, to then be described as making a 'mini suicidal gesture', for example.

Unfortunately, this dismissive language can arouse a more dangerous suicide attempt. It is extremely difficult to express desperation in medical systems, including the emergency department, when clarity of communication may be taken as a sign that medical attention is not required.

## Borderline personality disorder

The most common 'personality disorders' seen in emergency departments are people who present with 'borderline personality disorder', usually after self-harm.

There is often a stand-off between people with a 'borderline personality disorder' diagnosis who regularly self-harm (usually by burning, cutting or overdose) and emergency clinicians and cultures.

This is a very difficult area for everyone. Amid a setting where staff are dealing with physical trauma – people tragically harmed in some way, moving patients through, getting people beds, seeing to the child with a broken arm – in we come, having courageously dealt with our internal pain (too terrible to even articulate) by cutting our wrists. But we are not seen as 'innocent', as the broken-armed child is. Our valour is completely missed by the emergency staff because they feel impinged on by us.

Some emergency clinicians have told us how they often experience our 'behaviour' as a deliberate act against him/her as a person. Our actions are seen as wilful, immature, chaos-creating, evil even. This has a tendency to create a showdown and it can turn horrible.

There is an obvious need for education of emergency department clinicians by experienced consumers so that they are able to better understand the relationships between self-harm, borderline personality disorder, childhood neglect and abuse, and the role of self-harm in women (usually) looking after themselves.

## Self-harm

Not all self-harm that is seen in emergency departments is related to 'borderline personality disorder'.



At the present time there are many young people, teenagers and people in their early twenties who are cutting and burning. Some in the medical and research fraternities are calling it an epidemic of self-harm but that sounds to some of us more like a label to attract funding.

Nonetheless, many young people reach emergency services with scars and burns which must distress some emergency staff enormously.

Over the past decade services for people under 25 have escalated. There are now places to go and places to refer young people to and, at last, drug and alcohol services funding and psychiatry funding are organised in a way that ensures the two areas are talking to each other.

For more information on self-harm see the Our Consumer Place presentation by Merinda Epstein, Shame, Trauma and Self-harm: when self-harm is a sane response to an insane world: <http://www.ourcommunity.com.au/files/OCP/ShameTraumaAndSelf-harm.pdf>

### Bill of Rights for People who Self Harm

Deb Martinson, who has worked in the mental health consumer movement for many years, has developed the following Bill of Rights for People who Self Harm.

- 1 The right to caring, humane medical treatment.
- 2 The right to participate fully in decisions about emergency psychiatric treatment (so long as no one's life is in immediate danger).
- 3 The right to body privacy.
- 4 The right to have the feelings behind the self injury validated.
- 5 The right to disclose to whom they choose only what they choose.
- 6 The right to choose what coping mechanisms they will use.
- 7 The right to have care providers who do not allow their feelings about self-injury to distort the therapy.
- 8 The right to have the role self-injury has played as a coping mechanism validated.
- 9 The right not to be automatically considered a dangerous person simply because of self-inflicted injury.
- 10 The right to have self-injury regarded as an attempt to communicate, not manipulate.

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### Emergency Department Advance Directive

Elsewhere in the booklet there is information about how to write an Advance Directive, i.e. a statement of instructions.

The purpose of an Emergency Department Advance Directive is to 'direct' clinicians who don't know us to what we know experientially and what we need to expedite our movement through the emergency department.

Writing an Advance Directive for an emergency department is quite different from using an Advance Directive in other settings, but can be worth the effort.

They must be very short. There is no way in that hurried, emergency-whipped environment that anyone will have the chance, or desire, to read long stories.

It's a good idea to provide information, in point form if possible, about behaviour and treatments. For example:

- *I have school-age children at home. If anyone seeks to formally (another word for involuntarily) admit me, please ensure that my children will be taken to my mother Mary Smith (phone 4444 5566) or my sister, Susan Smith (phone 5555 6677). My children attend Smithville Primary School (phone 8888 9900).*
- *My attempts at suicide mostly occur when I feel neglect as I did as a child. If you try to reassure me by saying "It's only a small cut" or "It's an insignificant overdose", this will make things much worse, not better.*

It's also worth noting that Advance Directives are much more likely to be read and respected if they are signed by our doctor – preferably our psychiatrist. Involving a psychiatrist might mean using words and phraseology that you do not like, but it can help avoid a whole lot of unnecessary angst.

Always take about five copies of your Emergency Department Advance Directive into hospital if you can. These letters tend to disappear or get mislaid. Use one at the window on arrival and save the next one for the registrar. Give one to the liaison psychiatrist if he/she is called, and one to E-CATT. Keep one for later.

### Reclaiming our emergency department medical files

Reclaiming our emergency department files through Freedom of Information (FoI) can be useful because to be forewarned is to be forearmed. For example, it's useful to know that your file has a red warning sticker on it, even if it is not very nice to see it there. Surprisingly, perhaps, these marks of disgrace are actually quite rare.

As mentioned above, some of us utilise multiple emergency departments so locating scattered documents from lots of different hospitals can be tricky but it can be done on a single form. All we have to remember is the name of the hospital. Dates or even years aren't necessary as the hospital's records department should be able to track us down.

When using Freedom of Information it is perhaps more useful to think of ourselves as detectives looking for clues rather than lawyers casting around for someone to sue. If you already have a 'bad character' riddled medical history, using your records as



a weapon in an undisciplined way will probably make things worse.

If you attend emergency departments attached to private hospitals, records can be accessed through the Health Records Act 2001.

(See the section titled 'Accessing Your Files' for more on this topic.)

### **Surviving the emergency department**

Our fate in emergency departments will sometimes depend on our reaction to understandably testy clinical responses from emergency department staff.

If we can resist reacting to force with force, to rudeness with rudeness, to humiliation with arrogance, to patronising behaviours with threats and to staff fear with foreboding, things tend to be a bit easier for us.

However, this is a hard ask when we are so distressed and our understanding of the way emergency departments work is limited.

## **SECTION 2: Who's Who?**

## \* General Practitioners

**GPs and Mental Illness: Gardening Petunias with no soil, no water, no manure, but occasionally a faint light at the end of the tunnel.**

*2013 MadQuarry Dictionary entry*

General practitioners (GPs) are often our first point of call when we are having emotional issues or our friends have dragged us to the doctor kicking and screaming because we are distressed.

### Who are GPs and what constrains them?

As discussed in the chapter on Primary, Secondary and Tertiary Care, general practice is the cornerstone of primary care. GPs have primary responsibility as diagnosticians; they must have good practical and intuitive skills to pick up pathology as well as astute decision-making skills to decide which way to go next:

- Handle on his/her own;
- Send to specialist;
- Treat as an emergency.

When it comes to mental health there are a number of complicating factors, some of which are shared with other types of 'illness' and some of which are not:

- There is very little chance of getting anyone into a public mental health service unless they are floridly psychotic ('barking mad'). This means the GP is forced to try and cope, sometimes well outside their comfort zone.
- GPs, like all doctors, have been trained to see mental health problems as separate from 'real' health problems. In both Victoria and Canberra, mental health does not sit within the Health Department portfolio. It is more likely to sit with child protection, drugs and alcohol, disability, the elderly or homelessness.
- Some GPs are fantastic with people with a diagnosis of 'mental illness'. Unfortunately, such GPs can be unpopular with the partners in the practice as they are seen as creating 'dependent patients'.
- Medicare payment structures discourage GPs from providing long consultations, which many of us need most of the time.
- There are almost no mental health professionals in rural Victoria and very few in regional areas and in the poorest areas of metropolitan Melbourne. Some GPs spend an inordinate amount of time, energy and money trying to track down services for us, mostly unsuccessfully.

## What we can do for ourselves – Assertive Personal Management

Some GPs are really good with people with a diagnosis of mental illness. They give us generous time. They are interested in what we need to say and will go one step further to try to meet our needs. Unfortunately they are often in demand and have long waiting lists.

There are also, regrettably, GPs who are less interested in people with 'mental illness' and less able to assist us. They may treat us as less important than other patients, using words like 'dependent', 'histrionic', 'not really mentally ill', 'just behavioural' and so on.

Below is a quote from a consumer who has found a solution to this dilemma.

*"I found two GPs, one who is quite a long way away and is slow, sometimes keeps people waiting, but is brilliant on my mental health issues. I trust him. I wouldn't trust anyone else. Thank God he has saved me from having to see a psychiatrist. He's a very special doctor.*

*"I found another GP too. I wanted a physical health doctor. I know he is terse, sometimes even a bit rude, and difficult to communicate with and short. But he is quick, a great diagnostician, always on time, technically good and geographically convenient.*

*"The second GP doesn't know anything about my mental health history and I want it that way. I know lots of people want co-ordination between their treating clinicians but I don't! They would pollute each other; I don't trust his attitude towards people with 'mental illness'."*

### The policy environment

Although the fundamentals of good primary care remain relatively constant, what does change is the policy environment in which this practice must take place.

#### History

The Federal Government became more active in direct health policy (and mental health policy) with the establishment of the Federal Mental Health Branch by Labor Health Minister Brian Howe in 1992.

The Commonwealth, through the First National Mental Health Strategy, began to pour money directly into both state health coffers and into direct care through programs they were funding, giving the government an unprecedented opportunity to dictate guidelines.

In the case of both mental health and primary care, successive Federal Governments tried to influence state and territory health policy by making federal money conditional on 'performance and reporting'. Unfortunately for practitioners, and indirectly, perhaps, unfortunately for us, this policy-driven money brought with it an enormous amount of reading, research and paperwork for primary care clinicians.

GPs react differently to these imposed initiatives. Some were genuinely thrilled that

money was going into areas like psychological services, for example, where they had struggled for many years to find resources to help their patients. Some GPs resented this intrusion in their practice and became infuriated by the paperwork. Many GPs were also annoyed by losing (or the threat of losing) their autonomy.

As consumers, we need to understand this because it has the potential to influence both our care and our relationship with our GP.

Over time, federal intervention into health has become more blatant, with explicit programs in primary care and mental health, funded either directly through the Federal Health Department or through Medicare Locals, which have replaced Divisions of General Practice.

### Recent developments

In February 2011, the Australian Government released the publication outlining quite radical changes to primary care, *Improving Primary Health Care for All Australians*, and in August 2011 the National Health Reform.

The reform focused on a range of things, including better relationships between states and territories and the Federal Government.

Under the National Health Reform, the Federal Government aimed to shift health services from hospitals to primary care. This applies as much to people diagnosed with 'mental illness' as it does to any other member of the community.

The components of the 2011 National Health Reform which affect those of us with a diagnosis of 'mental illness' in a generic way are:

- Establishment of **Medicare Locals** which are "primary health care organisations established to coordinate primary health care delivery and tackle local health care needs and service gaps". At time of writing, most of us have heard of Medicare Locals but few of us understand what exactly they are intended to do.
- Building of more than **60 General Practice (GP) Super Clinics**, described as "medical facilities that support general practitioners, nurses, visiting medical specialists and allied health professionals to work together, generally in a single location, to deliver better health care to local communities". Again, many of us have heard of these but most of us are unsure of how they will work.
- Trialling of new approaches for the flexible delivery of treatment and management of diabetes through general practice. Many consumers are looking forward to these initiatives as so many of us have type 2 **diabetes** as a direct result of our 'mental illness' combined with effects of medications.
- Increasing access to after-hours services through the availability of an **after-hours GP helpline/hotline**, and giving Medicare Locals the responsibility for after-hours primary care responsibilities.
- **Personally Controlled Electronic Health Records (eHealth)**, which are described as "a secure, electronic summary of your important health information".

As these changes become more familiar, consumers will start to get a better feeling about the new programs and how we will be affected by them.

### ATAPS

In 2011 the Federal Government introduced legislation that would, they hoped, help to break down the mental health service impasse. They were heavily lobbied by allied health unions, particularly by the APS (Australian Psychological Association).

The result was ATAPS – Access to Allied Psychological Services. ATAPS provides Medicare funding that, for the first time in Australia, makes provision for federal money to subsidise the provision of a small number of sessions with a clinical psychologist or counsellor. It is complex and does not provide for the same refund for the different groups.

GPs have had a hard time getting their heads around this new scheme, as have psychologists. There are many issues.

- For us to access this program, GPs have to write a substantial Mental Health Treatment Plan. While we can experience this as intrusive and embarrassing, for many GPs the paperwork is loathsome.
- Definitions of eligibility are confusing and sometimes vary enormously between counsellors/clinical psychologists and GPs – often creating a situation where we get caught in a 'war' between the different clinical groups.
- Some GPs get cranky when clinical psychologists make a 'medical diagnosis' and then send 'clients' off to negotiate with the GP, who does not believe we fit the criteria. Having been told by the clinical psychologist that we would fit, we can get upset and then feel judged.
- Some GPs resent that they have to tell patients that they are not going to sign the document because they don't fit the criteria. This then effects the clinical relationship we have with both 'our GP' and 'our psychologist'.
- Some GPs are cross that the scheme has done little to absorb demand because too many clinical psychologists are simply adding the government rebate on to the private fee they normally charge.
- Clinical psychologists are often cross that GPs are making a call in an area where they are not qualified nor registered.
- The number of visits permitted under the scheme are very limited regardless from whom we seek help. This artificially contorts the sorts of therapies that can be provided usefully.
- Nothing in these initiatives changes the fact that there is a dearth of private therapy in the poorest suburbs in Melbourne, in country areas and regional cities.

For those of us with complex needs, often debilitating and arising from childhood trauma or 'mental illness' that requires psychotherapy, there is an item number in Medicare that enables our GP to refer us to a psychiatrist for up to 50 consultations per year.

Again, there are stringent guidelines which you should find out about if you think you might fit into this category.

## \* “Welcome to hospital. Meet your doctor.”

**Patient to doctor dialogue: noun** “Could you please put your power away for a while so I can get mine out?”

*2013 MadQuarryDictionary entry*

Student, medical officer, registrar, psychiatrist, consultants – it’s important when we are in hospital to know the difference between these different roles in the hospital hierarchy.

All of the people performing these roles (except the medical students) are qualified medical doctors but they do not all have the same power, responsibilities or time on the ward or unit.

It’s important to understand the roles of the different doctors (and other staff). If we don’t understand this we can spend a lot of time and wasted effort asking questions and trying to get responses from people who do not have the authority to give us answers.

It’s OK to ask anyone who is introduced as either ‘a doctor’ or ‘your doctor’ whether they are a medical officer, registrar or consultant (or indeed a student). Unfortunately, few doctors will divulge this sort of information voluntarily.

### Medical officers

Medical officers are generally in their second year post-graduation. That is, they have spent five years as medical students studying in university and in hospital placements. After this they would have done one year as an intern, being rotated around different areas of medicine in a hospital setting. The following year they would have gone on to become a medical officer.

Medical officers do not necessarily have an interest in psychiatry as a speciality; they do not stay in any setting for very long.

Medical officers will often be called ‘the doctor’ but it must be remembered that they are very inexperienced doctors who will be able to perform routine tasks but will not have the experience to make important decisions about our care.

It’s also worth noting that medical officers are rotated frequently so on many occasions you will be dealing with someone who only started their rotation in psychiatry three or four days previously. This magnifies their relative inexperience and makes it even more important to understand their limitations.

### Registrars

A registrar is the main doctor you will see when you are admitted to a public psychiatric Unit. The registrar will also play a major role if you use a public Community Mental Health Services.

Registrars are trainee psychiatrists. The traineeship lasts for at least five years and is supervised by the Royal Australian & New Zealand College of Psychiatry (RANZCP).

Registrars are more senior than medical officers; however, they are not yet qualified or registered as psychiatrists. Often patients do not know that the registrar is not a qualified psychiatrist.

They have more experience, greater responsibility and more power than medical officers but their power and authority is still limited. However, unlike medical officers, registrars have already made the decision to specialise in psychiatry so we know they have an interest in the area.

Registrars are always supervised by and under the guidance of qualified and experienced psychiatrists – called consultants (see below).

They will often be introduced as ‘your doctor’ and they will be on the ward and visible much more frequently than the consultants. They will have a ‘list’ of patients who remain under their care during the patient’s stay in the unit or on the ward, during which time they will be mentored, critiqued and assessed by the consultant to whom they are assigned.

Registrars will record anything you say and do and will feed this back to the consultant who will be the one making the most important decisions about your life.

### Consultant psychiatrists

Consultant psychiatrists are the top of pecking order in terms of clinical care. This does not mean they are top of the pecking order when it comes to management of the psychiatric ward or unit; that role usually goes to the unit manager.

Unlike registrars, consultant psychiatrists are qualified and experienced psychiatrists. They are often psychiatrists who have their own private practice and work a number of sessions (shifts) in a public psychiatric unit each week.

When you are admitted to a public hospital, you will be formally admitted by the consultant psychiatrist. (If you are admitted to a private hospital you will be admitted by your own psychiatrist.)

Once you are admitted you will go on to what is called your consultant’s ‘list’.

Consultant psychiatrists are the big guns in our care for the time we are in hospital and yet we see them much less frequently than we see registrars. This is the same in all fields of medicine. When the consultant psychiatrist interviews you the registrar will probably sit in. They are there to learn and most times they will take notes that will be committed to your file.

Consultant psychiatrists are often drawn to work in the public sector because the position gives them the flexibility to do research, or they may have a particular interest

in training new graduates, or they may have a particular commitment to public health.

Sometimes consultants will ask you whether you will consent to being involved in some research project they are interested in. Think carefully about this request. Your decision and reasons for making it could well be similar to your reasons for saying yes or no to requests for student doctors to sit in on an interview (see below).

Many of us forget the names of the consultant psychiatrist because we are introduced when we are in the first wave of admission. Don't be too embarrassed to get someone to write down the name for you. Things like addressing people by name are a good way to gain some control over the situation, as is making a rule to always shake hands and introduce yourself to any doctor you are seeing for the first time and (as a power-up ritual) each time you meet.

## Student doctors

You will recognise the undergraduate medical students because they travel in packs. They're also easy to spot as they are generally as frightened of you as you are of them!

Students will usually be escorted by the consultant psychiatrist, and you should assume that they will have been given access to your medical file even if you have not given your permission.

Student doctors do not necessarily have an interest in psychiatry (they will need to study this aspect of medicine as part of their training, whether they're interested or not), but they will have an interest in impressing the doctor who is interviewing you.

The consultant psychiatrist will call them together after speaking with you and will quiz their knowledge about psychiatry by asking them questions about your 'behaviour', 'ideas', 'diagnosis', 'treatment' and 'prognosis' (how long it will take you to get better).

Your permission should be sought first if students are to sit in on your interview with the consultant psychiatrist. It's OK to say yes or no, to ask questions about what it involves, or to make some conditions.

All these reasons for saying yes or no (and others we haven't thought of) are fine. You don't have to justify your decision to anyone and you can say 'no' regardless of whether you are an involuntary patient.

## Yes

Some of us will agree to be interviewed in front of students because we:

- Find it difficult to say no;
- Want to please the consultant;
- Fear that if we refuse there might be repercussions for us;

- Feel indebted to those who are providing care – this is one way we can repay this debt;
- Want relief from the boredom on the ward;
- Are genuinely intrigued to see what the students think of us;
- Hope to educate students from our perspective – to break down the discrimination. After all, most of us want our future doctors to be as free of prejudice as possible;
- Want to be useful;
- Don't know whether we're allowed to say 'no' because nobody has talked to us about it.

## No

Some of us will say no to allowing students to sit in on our interview because we:

- Know our rights and choose to exercise them;
- Don't want anyone else prying into our private lives;
- Don't want any other people making pre-judgements about who we are, based on limited and medically-biased information;
- Are working hard to get out of the hospital and fear these sorts of inquisitorial encounters will only set us back;
- Know this has a lot more to do with the welfare of the students than it has to do with our welfare;
- Don't feel it is our responsibility to educate the next crop of doctors.

## Hospitalists

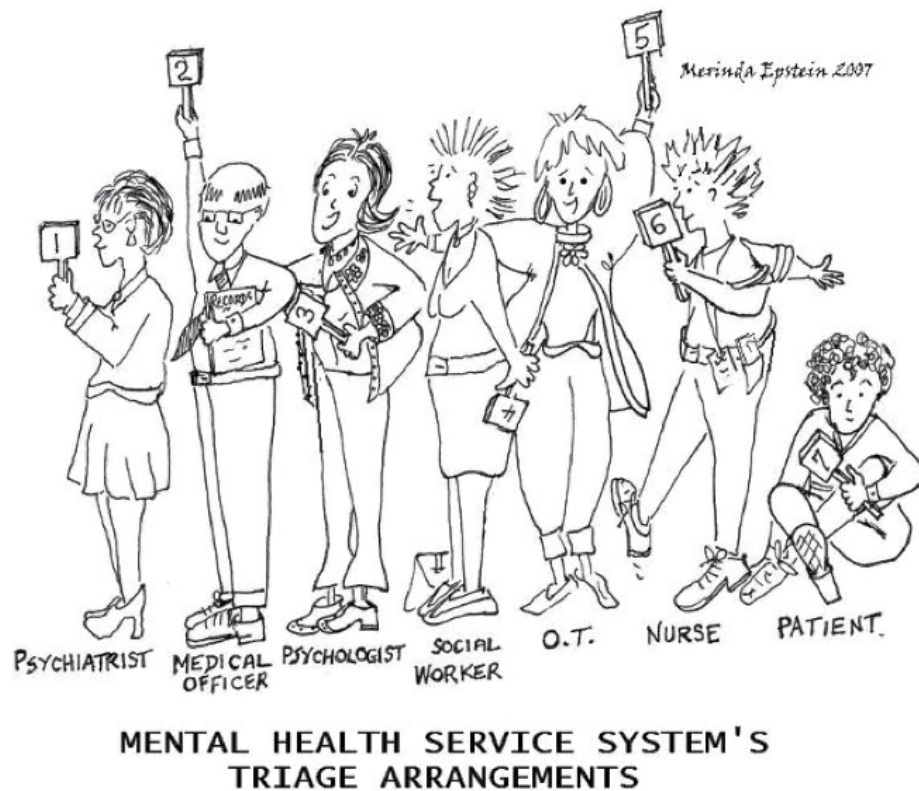
In some states qualified general practitioners (GPs) are employed in emergency departments as 'hospitalists'.

The role of the hospitalist is to learn about the movement of people through the emergency department, identify 'regulars', and work with those of us who need to visit emergency departments very frequently for a variety of reasons.

The goal is for the hospitalist and 'patient' to find new and more sustainable ways to get very real needs met.

At this time, we have no hospitalists in Victoria but the model has worked well in NSW.





## E-CATT Teams

Working alongside the doctors in many hospitals around Australia, and all large emergency departments in Victoria, are the E-CATT (Emergency Department Crisis and Assessment Team) nurses.

This service runs 24 hours a day in most public metropolitan hospitals. The E-CATT nurse is, amongst other things, required to assess every person who has self-harmed, taken an overdose, has a mental illness history, or is simply known to the staff, before we are discharged.

This pushes the limits of the very small E-CATT team. Delays can result and this often annoys other emergency staff who need the bed and don't need us hanging around waiting. The situation can escalate when we are seen to fit into that group not believed to have a 'serious mental illness'.

Understaffed E-CATT teams can also get pressure from other clinicians to push us through, leading to a cursory glance and discharge. When this happens after a suicide attempt it leaves us with a range of feelings, from bitter self-hatred to helplessness to anger.

Unfortunately it can also lead directly to a subsequent suicide attempt – and maybe a much more dangerous one. It's not our fault that emergency departments are not

designed respectfully for us. The chaos of the setting and emotional crisis is a dangerous mix, and is often too much for what the E-CATT nurse (often just one) on duty.

## \* Psychiatrists

### A shrinkage of psychiatrists: collective noun

2013 MadQuarry Dictionary entry

A psychiatrist is a qualified medical doctor who has obtained additional qualifications to become a specialist in the diagnosis, treatment and prevention of 'mental illness' and emotional problems.

Because of their medical and psychiatric training, psychiatrists are supposed to be able to view illness in an integrated way by taking into consideration the related aspects of body and mind. (However it is a common consumer view that their training is deficient in the area of the social and the cultural.)

Psychiatrists are trained both to recognise and treat the effects of emotional disturbances on the body as well as the effects of physical conditions on the mind. Some are able to do this better than others; that ability is not just to do with their academic credentials.

Psychiatrists claim that this multi-dimensional aspect of their training is important as many emotional disturbances affect various parts of the body and physical illnesses can certainly affect the mind. In principle, a psychiatrist's medical and psychiatric training allows both the physical and emotional to be kept in perspective.

Life with a psychiatrist is much more complex than it may at first appear. What any one of us experiences may be totally different from what another experiences, even when we are seeing the same psychiatrist. This is, in part at least, because so much of what psychiatrists do depends on the individual relationships we create together. This is particularly so with psychiatrists who are more oriented towards psychotherapeutic interventions.

## Qualifications & registration

All doctors trained in Australia, including psychiatrists, have a medical degree. In most cases, this is an MBBS (Bachelor of Medicine and Bachelor of Surgery), although doctors trained at Flinders University of South Australia are awarded a BM,BS (Bachelor of Medicine and Bachelor of Surgery), and graduates of the University of Newcastle in New South Wales are awarded an equivalent BMed (Bachelor of Medicine). If they're trained overseas, the qualification may be different again; for example 'MD' (Medical Doctor) in the United States.



Once general medical students have completed their initial training they are required to serve a further year in a public hospital to gain experience. They cannot become fully registered until this internship is completed. Following this, the doctor must serve a further year as a Resident Medical Officer.

In Australia and New Zealand, specialist training for doctors to qualify as psychiatrists is conducted by the Royal Australian and New Zealand College of Psychiatrists (RANZCP). The college's program for post-graduate training in psychiatry takes a minimum of five years. Whilst undertaking this training, doctors are called registrars.

It can be a good idea to check that a potential psychiatrist is a registered doctor. Qualifications and registration are supposed to be prominently displayed in the psychiatrist's rooms. However this is not always done – sometimes psychiatrists who are sensitive to the unhealthy power differential between patient and clinician prefer to put these symbols of power and qualification in a less obvious place.

In any case, public display of qualifications is not always helpful. Some of us feel a bit silly asking to examine these – “Excuse me, may I walk around your office and check your official documents, Doctor?” It's often easier to contact the RANZCP and simply check that everything is bona fide. Call (03) 9640 0646 or email [ranzcp@ranzcp.org](mailto:ranzcp@ranzcp.org).

It's important to note that more and more qualifications are not necessarily an indicator of a better clinical experience. For example, we have known some outstanding registrars who have taken a long time to pass their final exams (possibly because they are too busy being good doctors!).

## Style of practice

Most psychiatrists use a 'medical model' approach. That is, they develop expertise in the diagnosis and treatment of psychopathology, often using psychiatric drugs (psychiatrists are allowed to prescribe medical drugs). In general, psychiatrists have a primary interest in diagnosis, treatment (in whatever form it takes – sometimes augmented by various forms of psychotherapy using 'talking' and 'behavioural' approaches), and prognosis.

It is OK to ask about the professional interests, experiences, theoretical underpinnings, preferences, fees policy and engagement rules within which a particular psychiatrist works. The psychiatrist does not have to answer but the response will tell us a lot anyway.

Of course, some of us don't want to know all this detail. That's OK too.

If you do want to know more about the style of treatment that your psychiatrist uses, it's useful to have some background first. There are many approaches but for simplicity, this publication introduces three of the most common: psychopharmacology, psychotherapy and behaviour therapies.

Note that many psychiatrists work multi-dimensionally. They may be interested in psychotherapy, may indeed have a specialised interest in this area, and still also use pharmacology. Their practice may be described as 'eclectic'.

## Psychopharmacology

Psychopharmacology (which describes the practice of psychiatrists who have a primary interest in brain chemistry and pharmaceutical drugs) is a major area of practice for psychiatrists.

Sometimes individual psychiatrists who fit into this category develop a particular speciality; for example, '*polypharmacology [administration of many drugs together] for Bipolar Affective Disorder*'.

Psychiatrists who have a primary interest in psychopharmacology are likely to be interested in that set of illnesses that are known to have a strong chemical aetiology (or background). The sorts of diagnoses that might be of interest would include bipolar affective disorder, the schizophrenias, schizoaffective disorder and also some of the depression and anxiety disorders which are 'clearly biochemical'.

It is possible that we may be referred to these sorts of specialists for specific advice that our own psychiatrists believe will prove useful. However, compared with other treatment styles, pharmacologically oriented psychiatrists tend to see us less frequently, maybe once a month, and for less time, maybe just 15-20 minutes at a time. Their interest might predominantly be in how we are reacting to the medical drugs.

The practice of pharmacologically oriented psychiatrists, and their interest in those of us who seem to have diagnoses at the biological end of the 'illness' scale, does not mean we have lived singularly uncomplicated lives and that psychosis, for example, just landed on us like a biochemical bolt from the blue. There are many of us who still need or desire a skilled psychiatrist or clinical psychologist interested in 'talking therapies'.

It's important to note that we can make choices about our 'treatment'. A clinician who's good with medical drugs is perfect for some people. Some of us have tried the talking therapies, found them of limited use and just want our medications monitored.

## Psychoanalysis

'Talking therapies' are diverse. Some are formalised into very structured, deliberate patterns of interaction between doctor and 'patient', incorporating practices that have been tested over time.

Some of the more structured therapeutic approaches are very predictable in terms of the relationship, may have 'contracts' that patients have to agree to before therapy is commenced, and may have rules about things like interaction between visits.

These sorts of therapies come in different forms but they include perhaps the most famous, psychoanalysis, which was developed by Sigmund Freud and is maintained in structure from Freud's original paradigm. If we sign up to undertake therapy which is psychoanalytical in origin it is probable that we'd visit the psychiatrist up to three times a week.

There are two common problems that many of us encounter with psychoanalysis. The first is the cost – Medicare will not subsidise such frequent visits. The second problem is that some of us will fall over completely trying to analyse ourselves! It sometimes becomes so overwhelming that the rest of our life disappears or becomes secondary

to the analysis. Not surprisingly, this can be harmful for your mental health.

Notwithstanding these two not insignificant problems, many consumers have reported that there are some very good psychoanalytical practitioners who have been very helpful.

### Supportive psychotherapy

Psychoanalysis is not the only 'talking therapy' approach; in fact, there are dozens of variants.

Psychotherapy is another approach. This is all about learning new things, reflecting, analysing and practicing, both for the 'patient' and the psychiatrist. In fact, we actually do very little of the work in the session with the psychiatrist. It all happens in the shower and in bed, the toilet, or car (or anywhere where there is head space time) during the hours and days between sessions.

There are many sub-sets of supportive psychotherapy but what they have in common is a reliance on healing through the relationship the patient has with the doctor. The relationship is paramount. This relationship is born out of regular visits, often weekly, to the psychiatrist, which usually last for about 50 minutes. If consultations total less than 50 a year, they are generally covered by Medicare.

Psychotherapy is very different from other forms of medicine and it does have its ups and downs but for many of us it works. Because the relationship is so important, it's crucial that the psychiatrist we see for this type of therapy is the right person for us.

Many consumers think that all psychotherapy is expensive gobbledegook and see 'talking therapies' in general as a waste of time and a waste of their taxes. Many consumers also heavily criticise psychopharmacology and its relationship to 'Big Pharma'<sup>1</sup>. There is no doubt that consumers have a wide range of political and personal beliefs and therapeutic preferences. No one view is more 'worthy' than another.

“ There's something rather reassuring as I drive across town every Friday in peak hour traffic to know that I'm mad. All the way through traffic jams I sit up there practicing what I am going to say to my psychiatrist when I get there. The car is on auto control and I am concentrating on every sentence, inflective, special tones, the plot and facial muscle control. The man in the car next to me looks at me oddly. I must have been gesturing a bit too flamboyantly. When we get there, of course, there's always a distraction and we talk about nothing I had practiced in the car. But, you know, so many of us do it and we all know if we are honest that the therapy has already taken place in the car long before we reach our destination.” – Merinda Epstein

<sup>1</sup> Big Pharma is the consumer terminology for the pharmaceutical industry which some consumers believe is a huge multinational industry which poisons people, rips off taxpayers and which has far too much say in health policy. Naturally, not all consumers believe this. See the Our Consumer Place Psychobabble publication ([www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au)) for more on this discussion.

### Cognitive and behavioural therapies

This set of therapeutical approaches divides consumers perhaps more than any other. Some people get a lot out of them and others absolutely hate them.

This style of therapy includes cognitive behavioural therapy, dialectical behavioural therapy, or any one of the new behavioural therapies that are emerging. Behavioural therapies differ from pharmacological and psychotherapeutic approaches. They are complex and multifarious; however, as a crude idea they tend to be:

1. short term;
2. timetabled;
3. full on for this period of time – even daily;
4. strong on boundary definition;
5. concentrated on present day skills rather than our past;
6. very practical;
7. reward-based;
8. involving sanctioning of 'wrong' behaviours ('therapy interfering behaviours');
9. sometimes didactic learning based; and
10. at their most 'pure', quite rigid in design, expectation and even exit rituals.

Some consumers sing the praises of cognitive and behavioural therapies. People say they know what they're getting, the boundaries are very clear; they see improvement for themselves, and group work provides a very useful learning 'replay experience', even when it's not so pleasant. They say that progress notes and constant feedback helps, as does praise for their effort and the gains they make. Many like the fact that the whole parcel is short and they can aim for something in the short term.

On the other hand, many consumers dislike cognitive and behavioural approaches. People who have an aversion to this approach are often those who like playing with ideas – they don't like what they experience as a straight-jacketed, dictatorial approach and they object to what they experience as patronism by doctors. They are often creative thinkers who feel stuck in a jar in this type of setting, with every approach they make to be themselves seemingly forbidden.

This division depends on many things but one of them, we think, has to do with whether we are concrete or abstract thinkers.

### Practice differences

Apart from broad social and cultural determinants and particular preferred treatment methods, psychiatrists also have individual practice priorities, habits, communication skills, likes and dislikes. They have a 'worldview'.

Some psychiatrists take loads of notes, some take none. Some charge the recommended fee whilst others are quite expensive. Some talk about themselves and others don't. Some have a messy office and squeaky chairs; others have spotless offices.

There is no right or wrong about all this but it's important to back our own judgment and if things don't feel like a good 'fit' it's better to extricate ourselves from an unhelpful relationship early.

## The art and science of psychiatry

No psychiatrist is belief-neutral and no psychiatrist sits outside the larger social forces of our society. Gender, culture, ethnicity, social class and sexual preference are all factors that affect the clinician's practice – the decisions they make and the actions they take.

Of all the clinical groups working in the area of mental health, psychiatrists have the greatest power to assert their social values and beliefs on to others. This is because the institution of psychiatry is such a powerful social force.

Despite attempts to promote the science of psychiatry, many psychiatrists (and many of us) recognise that much happens which is – at its best – closer to art, and, at its worse, conjecture.

## The relationship

Transparency needs to be an aim of the psychiatrist. At the same time **we** (consumers) need to remember that the psychiatrist's room is not a confessional – we don't have to tell our psychiatrist everything. There is nothing like the power of a secret well kept!

At the same time, for many of us who 'keep' private psychiatrists there is great relief in knowing that someone is being paid to listen – mostly respectfully – to what we have to say.

Provided we have enough money to support this habit it can be very healing to have someone to talk to. It's also a good way to unburden oneself on someone who is paid to take it. Having these conversations with family and friends just isn't on for many of us. It's also a way we can show that we are taking responsibility for our own 'stuffed up lives' (well, hopefully not absolutely stuffed up!) and only dumping on someone who can't be hurt (at least, that's what we tell ourselves).

However, how do we know when it's become too easy, too much of a luxury? Many of us have frequent or not so frequent pangs of guilt for using up professional time that we don't deserve: *"Will she ever say, 'enough is enough, you're cured, go away?' How will we react when that day happens?"* We may wonder about the hidden fears we have about 'going it alone'.

Many of us wonder whether we've become 'institutionalised' in a sociological sense – becoming dependent on regular visits.

The amount of ourselves caught up in this relationship can be huge, but this is often not reciprocated, leaving us feeling guilty for allowing ourselves to become dependent. Remember, this is about your whole life but it is only the psychiatrist's job. Dependency in this scenario is not of our making.

The relationship between a psychiatrist and a mental health consumer is a big topic,

and discussed further in the section titled 'Understanding Clinical Relationships'.

Fees are another big issue when it comes to private psychiatrists – see the section titled 'Money Matters' for more on this.

## \* Psychiatric Nurses

**Compassion Fatigues: noun** Name tags, door swipes, multiple keys, staff toilet privileges, and five-metre safety zone behind bulletproof, sound resistant trenches.

*2013 MadQuarry Dictionary entry*

Psychiatric or mental health nurses are the lifeblood of the mental health system.

They are registered nurses who hold a recognised specialist qualification in mental health nursing.

They work in a huge variety of roles and in a range of primary, secondary and tertiary mental health settings, including (but not restricted to) community mental health services, acute units, public and private hospitals, and as case managers, as part of crisis teams and in specialist mental health services, working with youth and aged care, for example.

To become a psychiatric nurse, you must first become a registered nurse (three years), and then you must get a post-graduate degree or post-graduate diploma in mental health nursing (one year).

The psychiatric nursing profession is served by the Australian College of Mental Health Nurses (ACMHN: [www.acmhn.org](http://www.acmhn.org)), which provides courses, information and credentialing for members. The ACMHN represents mental health nurses and the profession as a whole; in such a way, it's also a bit like a union.

Registration of the profession is carried out by the Australian Health Practitioners Regulation Agency (AHPRA – [www.ahpra.gov.au](http://www.ahpra.gov.au)). Consumers can check a nurse's qualifications and make complaints about a psychiatric nurse to AHPRA.

All nurses must register for an Annual Practising Certificate and provide evidence of a minimum 20 hours clinical study each year.

## Hierarchies of power

Psychiatric nurses are the group in mental health with the greatest numbers and the least status.

There are some exceptions to this rule, however. As in physical health, many psychiatric nurses aspire to and gain senior positions in management – head nurse or unit manager, for example – giving them considerably more power within the service.

Going even further afield, there are psychiatrically trained nurses who gain positions of considerable esteem and power in more general public hospital positions or in the state bureaucracy which run mental health services in Victoria.

Having said this, however, the general premise remains true. Nurses in most positions in private and public services are seen by some patients and some other staff as relatively low in the pecking order. This underlies their practice and influences their relationships with us and with the service in general.

## Nurse practitioners – mental health

Nurse practitioners are senior, experienced nurses who have opted to gain promotion whilst staying as hands-on nurses. Their introduction was, in part, to try and offer promotion opportunities for outstanding clinicians who did not want to go into a managerial stream in order to enhance their career. Nurse practitioner positions were created across all health areas including mental health. Nurse practitioners, as senior clinicians, may have responsibility for a number of tasks that had previously been the responsibility of doctors. This frees up medical practitioners, particularly in the public sector, to see more people and spend more time with people in need. Two of the tasks nurse practitioners may now do is prescribe pharmaceuticals (in a restricted way) and complete some reports and paperwork, tasks which have historically weighed down clinical time.

## Care and treatment plan

As a mental health 'patient' in an acute setting, our care plan (or treatment plan) will outline what nurses (mainly) have to do to look after us in the most timely and professional way.

It may contain information from us about the most appropriate way to care for us, including information from our Advance Directive if we have one, but more importantly (from most clinicians' standpoints), it includes summary statements from registrars, consultants or private psychiatrists, as well as information about medication and what groups we must attend.

Most consumers believe we would do much better if our care and treatment plans were made in an authentically collaborative way. A lot of what is said to be collaborative decision making is a bizarre farce. Many of us answer what we know nurses, representing the system, want us to say. Sometimes this is imperative (we want our children back, for example) and sometimes actual collaboration isn't an option.

Nurses are expected to formally admit us to a unit, orientate us and introduce us to other inmates. Often this doesn't happen or is not done well and we get left alone and scared in an environment that is completely foreign to us. Nurses are expected to write a treatment plan **with us** on admission. Often this doesn't happen either and the 'collaboration' is merely a signature on a document already written within the safe glass walls of the nurses' station. Unfortunately these practices smudge in our minds the genuinely dedicated practice of the nurses that Isabell Collins evocatively calls, 'Light a Beacon Nurses' who practice what she describes as 'Beauty of Care'.

## Confidentiality

Your medical information will be treated confidentially, right? Well, there's confidentiality and then there's confidentiality.

## Case histories

The term 'case history' refers to our history as seen through clinicians' eyes. It's our story but it is not something we write or can control. It's sometimes helpful to just think the psychiatric unit has borrowed our story for a while.

Our case history may include our schooling history, illness and mental health history, family history, current health and support status, as well as our financial and housing situations.

All of this information may be available to the clinicians tasked with providing our 'care'.

Psychiatric nurses may add to our case history as a result of one-on-one conversations with us and 'observations' of our 'behaviour'. They may include notes on what we have said, as well as commentary on whether we are attending the groups we are expected to attend (and whether we're doing so graciously), and comments on our demeanour (aggressive, passively aggressive, quiet, contemplative ...). Unfortunately we have no say over what is included.

Consumers all over Australia have complained bitterly about both what is recorded about them in an acute setting and also how it is recorded. Private phone calls have turned up verbatim in a medical history accessed through Freedom of Information, as have private conversations with other patients, family and friends. The ethical problems this presents are mind boggling, as is the consequent lack of action by other clinicians to correct the file.

The important notion that nurses are collecting highly sensitive information to put in a document that can never be changed seems to have got lost in the translation to nurses undergoing clinical training.

## Handover

The way that nursing staff communicate from the morning shift (usually starting at 7am/7.30am) to the afternoon shift (usually starting at 3pm/3.30pm) and from afternoon shift to the night shift (usually starting at 10pm/10.30pm) is through an oral report about everyone in the unit/ward handed from the nurses finishing their shift to those starting their shift.

The nurses will have also have written notes about us which the next shift reads but at handover the nurses will provide more detail about what they had experienced and found out during the previous shift. All staff on the next shift, regardless of whether they are our designated contact staff, will be privy to this information.

Seasoned consumers know the '20 minutes to go' handover drill, where nurses suddenly appear and ask us a barrage of questions in front of anyone who happens

to be around. They demonstrate little interest in our answers before darting back to write their notes that will be read to everyone in the handover room regardless of whether they have any legitimate interest in our particular 'case'.

This is no different from the model used throughout medicine. However the content in psychiatry is entirely different. No one is writing about sugar levels here. It's about us – our person, our self, our reputation, our honour, our intimate relationships, our trauma and our abuse. Consumers argue there is a case for psychiatry to do things very differently.

### **Multi-disciplinary teams**

In many settings psychiatric nurses work in multi-disciplinary teams – your team may consist of a registrar, a nurse and an occupational therapist, for example. These teams occur both in acute inpatient units and in the many teams that operate out of the Area Mental Health Services.

Organising staff in this way is an attempt to bring the expertise of the different clinical groups together to enable us to receive the 'best possible' practice.

However, perhaps the most important thing to remember is that teams can expand and contract – this affects who is given intimate information about you.

### **Confidentiality considerations**

In the context of case histories, multi-disciplinary teams and the tradition of handover, we must be careful about what we say and to whom. Every nurse in a multi-disciplinary team, regardless of whether they are working in 'the community' or in hospital, is required to report back to 'The Team' everything they judge to be important.

Many consumers misunderstand the way the word 'confidentiality' is used in these circumstances. 'Confidentiality' always means 'confidential to the team', not confidential to the particular staff member we are speaking to at the time.

There are some fantastic nurses who draw us in by their competence and caring and we may start talking to them about things that are so personal that we have never spoken about them to anyone. It is incumbent upon the nurse in this context to let us know that this information will be passed on to The Team and may be shared at handover. They don't always do so.

For more about privacy and confidentiality, refer to the section titled 'Privacy, Secrecy and Confidentiality'.

### **Contact nurses**

Generally in Victoria, patients admitted to a psychiatric unit are designated a particular 'contact nurse' (or 'primary nurse') for each shift, except for the night shift when the ratio of nurses to patients is much lower.

Almost always there is a list of nurses and designated patients for that shift clearly displayed for all to see in the ward or unit. It can be terribly embarrassing to see your

name on a list like this; while those working in this environment day after day seem to simply lose sensitivity to these things, many consumers find it shaming.

Each contact nurse has responsibility for roughly eight to 15 patients. In many units an effort is made to have the same contact nurse come back to the same group when they are next on duty.

As a patient, we are expected to pose all our questions to our assigned contact nurse and leave the other nurses alone. This is great when s/he is competent, enthusiastic and available (i.e. not on a lunchbreak), but not so great when they are not.

### **Charge nurse or head nurse**

If you are admitted to a psychiatric unit, whether it be private or public, it's a good idea to find out who the charge nurse is. They run the unit. They have a lot of authority, even over doctors. It's the place to go if you have a complaint.

### **Quality of practice**

Many psychiatric nurses work incredibly debilitating shift work (though some like the shifts). Even though they almost never get the press (nor the money) of psychiatrists, and rarely get the overt thanks and appreciation that they might get in a maternity unit (say), some act with such skill, grace and kindness they should be better acknowledged.

There are unfortunately also a number of psychiatric nurses who do the wrong thing. These might be big things which are inexcusable (see the section titled 'Making a Complaint'); however much of the behaviour that upsets us happens within the culture of the institutions of psychiatry. Many of us have felt these institutions have robbed us of our self confidence, figuratively undressed us, disempowered and infantilised us. We may feel unable to speak and scared to be angry.

In such a context, let's pretend a nurse is really off-hand and rude to one of us in a hospital setting. Under the conditions above and depending on our personality and world view, we might react in one of the following ways:

- Scream and yell because this feels like the last straw, and nurses are the only group that have sufficiently low status for us to feel strong enough to let fly at them.
- Try to become as invisible as possible, as we tend to do when we feel shame, or move to self-harm punishment mode, knowing that our reaction is being 'observed' and that because we are the 'patient' we must be wrong, leading to still more shame.
- Try to make a formal complaint.

Unfortunately, such actions tend to leave us frustrated (as in the case of complaints that go unanswered or unacknowledged), and can often lead to more guilt, more shame, more judgement, and more trouble for us – even though it was not us that was rude in the first place!

### **Good practice/brave practice**

What is experienced as good nursing practice is different from nurse to nurse and consumer to consumer.



Some things that we have experienced as excellent practice might be questionable to some nurses. Many of us believe that the number one characteristic of good nursing is bravery: bravery to take on a bad practitioner; bravery to act on our behalf, bravery to push the boundaries of professionalism and bravery to be whistleblower if an extreme circumstance calls for it.

## \* Case Managers

**Treatment Plans in Private Hospitals: noun** I am over programmed already. There should be a program limitation statute.

*2013 MadQuarry Dictionary entry*

The role of case manager emerged in the 1990s as the emphasis in the public mental health system spun around to pay greater attention to people diagnosed with psychotic illnesses.

In a mental health setting, your case manager might be a mental health nurse, psychologist or social worker. If you want to know what sort of training someone has had it is fine to ask them.

Case managers can do a 'mental state examination', which is like a clinical assessment – see here for more on this: [http://en.wikipedia.org/wiki/Mental\\_status\\_examination](http://en.wikipedia.org/wiki/Mental_status_examination).

Case managers are there to 'manage' our day-to-day living, which may include: our emotional and mental wellbeing; how we deal with stress and illness; our safety and the safety of others; our friendships and relationships; our work, leisure and education; our daily living skills; our physical health; our income and housing; and our rights and advocacy.

### Treatment plans

Treatment plans are known in some states as 'management plans' and that's what they tend to be. Treatment plans are supposed to be drawn up collaboratively with our case managers, though in reality very rarely does that happen. It's much more common for a case manager to create a treatment plan and then elicit our signature.

Often people who are 'assertively case managed' within the public mental health system are people who are deemed to be 'seriously ill'. Many will have huge files or histories and in these documents will possibly be, either known to the 'patient' or not, many cruel labels and assumptions. These may well include words like 'attention seeking', 'acting out', 'refusing care', 'non compliant', 'unstable' and many more.

Although the system officially wants co-writing of treatment plans, the structure

and conditions under which psychiatry itself, and the public system in particular, works mitigates against this dual decision making taking place.

In the private sector there is more time and money to make dual decision-making possible but there are still many structural problems, including greater power to individual psychiatrists who might not want power shared in this way, even when the case manager is enthusiastic.

These are some of the reasons the process of writing a treatment or management plan morphs back to the same process of one-sided decision making that many consumers are used to:

- Many consumers are so hurt and angry with a clinician that they couldn't be bothered doing the case manager's work for him/her.
- It's in the wording – how can it be a genuine sharing of power when one person is there to 'manage' the other?
- If done well, it's often a slow process, and many case managers are run off their feet.
- It takes little account of our lives outside our 'illness', whilst many of us seriously want holistic medicine.
- Such plans are too often consumer unfriendly in their structure, or patronising and condescending in their effect, and we know we'll never change that so why waste our time on them.

It's important to know that we don't have to sign if we don't agree with the plan or the language in it. However, the consequences of not signing can mean we become 'labelled' within the system attracting such words as 'trouble-maker', 'uncooperative', 'difficult', 'uncompliant' or 'treatment resistant'.

[See Judi Chamberlain's *Confessions of a non compliant patient*: <http://www.power2u.org/articles/recovery/confessions.html>]

### The trouble with being 'managed'

Many people who have been diagnosed with 'mental illness' have been 'case managed' for much of their lives. They are 'case managed' by Centrelink, they are 'case managed' by Area Mental Health Services (the community arm of public mental health services), they are 'case managed' by services providing support in finding work and finding accommodation.

There are many of us who hate the language of 'case management', finding it controlling and inherently disrespectful of our capacity to run our own lives, make decisions for ourselves, and operate without rules and regulations demanded from bureaucrats.

Some of us are sceptical about the case manager concept and the way it is practised – whether we have been diagnosed with a 'mental illness' or not, most people do not want our lives managed. Many of us would feel more comfortable with the term (and practice) of an individual's 'service manager'. It's a common consumer refrain: "*I'm not a case and I don't want to be managed!*"



## The paradox of case management

'Case managers' believe that a significant part of their job is to encourage, cajole, document and even 'empower' us to manage our lives more effectively. Many consumers argue that 'empowering' is not something any clinician can do to us. As soon as another person tries to empower us this is evidence that they have considerable power over us – empowerment can only ever be bestowed by someone who has institutional power over the bestowed-upon. The best a case manager can do is look at their own behaviour and stop disempowering us.

It is, of course, impossible for us to self-manage at the same time that we are 'being managed'.

## Good case management

Many consumers report three things that they believe make for a good 'case manager':

1. **Personal qualities.** Personal qualities of empathy and humility, a person who loves his/her work, does not have 'compassion fatigue', is committed and reflective, moves through the world confidently and has good-quality supervision from experienced staff. Fortunately, there are many 'case managers' that fit this bill and continue to operate under difficult circumstances in what can be a thankless task. We admire you. We thank you!
2. **Someone who is here to stay.** Distressed consumers working with distressed 'case managers' is a recipe for something to snap. Often it is the 'case manager'. The turnover rate in some of the most stressful areas of case work is high. Rapid turnover of staff is unsettling and particularly unfortunate for many of us who battle with issues of trusting and reliable interpersonal relationships.
3. **Good management.** Consumers need managers to be accessible, able to relate to the consumer experience and realistic about what does and should happen under their watch. In terms of the merry-go-round of 'case managers' they need to be proactive in recruiting, supporting and recognising emotionally fatigued staff.

There's information elsewhere in this booklet designed to help us write a letter of appreciation for those case managers who have been faithfully at our side as we have made wise decisions. It's good to write to them. They need our support.

## The relationship

'Case management' can be a fraught role. In some ways, it's a bit no win. Some of us are lonely, sad, housebound, estranged from our families. Our regular interaction with our 'case manager' might provide vital interaction with the world.

However, we are only one and the 'case manager' could have 20+ people to keep a clinical eye on. This is fraught – difficult for the 'case manager' but even more difficult

for us. Our needs must be bent and bruised around a reality that this person, perhaps the person we talk to most often in the world, is nothing but a worker.

As flagged above, many consumers argue that the very term 'case management' can damage client/clinician relationships and set up barriers to communication. They would prefer the term 'service manager', believing this more accurately describes the job these clinicians do.

## Making a complaint

It is the case manager's job to ease the navigation channel for us to move through and to the services and resources we are entitled to and need. They are not there to make judgement upon us, to make us feel inadequate, to hand out ultimatums, or to liaise with us in any other way than the way they would want to be negotiated with themselves.

Being 'mentally ill' and broke are difficulty enough; being judged, contracted into subservience, treated as not having a 'real mental illness' or dismissed because we are on a Community Treatment Order can do great damage to our souls. We may have made mistakes in our lives, we may have illnesses that test our energy levels, we may take therapeutic drugs that make us unattractive or fat or drooling or zombie-like – but these are no reasons to accept 'case managers' who are rude, bossy, write nasty things about us or pretend they have consulted us when they have not.

None of these behaviours should be part of any case manager's modus operandi.

If you do come across such poor treatment, you may wish to complain. Every time someone complains it opens up an opportunity for someone else to feel strong enough to do likewise. Plus there's a chance that you might contribute to a change in the system!

Of course, not all of us will want to complain. Many of us have very real fears about the awful consequences of disagreeing with 'our' case manager. Despite the ideal which is loftily promoted, few of us are going to be self-determining in the short term if this means losing the kids to the state or being thrown back on a Community Treatment Order. This is obviously very unhelpful for us when we want to build autonomy and develop independence from the service system.

Real fears notwithstanding, there are groups that can help us move into this place of social and cultural interdependence from which safer options to move away from case management can emerge. These include community legal centres, and the Victorian Mental Illness Awareness Group (VMIAC). There are also some wonderful wells of inspiration coming out of the Psychiatric Disability Support Sector (PDSS).

See the section titled 'Making a Complaint' for more on this topic.

## \* Clinical Psychologists

**Clinical Psychologists: plural noun** Did you say I was a counsellor? Definitely NOT! We're not counsellors. Good grief! We need a Community Awareness Campaign about this.

*2013 MadQuarry Dictionary entry*

Clinical psychology is the branch of psychology interested in the diagnosis and treatment of mental disorders.

Psychologists cannot prescribe medications, but they may provide individual or group therapy to people with 'mental illness'.

Some clinical psychologists follow the writings of important theorists such as Jung or Freud. Others have more eclectic practices. They might use psychotherapeutic models, a variety of different 'talking methods' that include unravelling the past, or methods that concentrate more on the present and the future.

At the present time, various forms of behaviour therapy are preferred, cognitive behaviour therapy being one of the most common. See below for more on this.

Clinical psychologists are just one group among many groups of practicing psychologists. They may also work in the fields of research, human development, sports, industry, media and law, for example.

### Styles of practice

Everyone who trains as a psychologist completes an undergraduate course that has been dubbed by some of us 'Rats & Stats', in reference to its positivist interest in research. Positivism is a science methodology that assumes that knowledge comes from evidence, which in turn comes from large-scale, statistical research; at its best, randomised, control trials. Psychologists pride themselves on the science of their trade.

Clinical Psychology is the branch of psychology that is interested in psychopathology; that is, the study of the causes and development of psychiatric/psychological disorders.

Even though clinical psychologists don't use medical drugs, they usually ascribe to a very medical model of practice. Sometimes they deny this; however, like psychiatrists, the clinical aspect of their training prepares them for identifying, classifying and 'treating' psychopathology.

Clinical psychologists don't practice with pills and potions. They cannot prescribe psychiatric medicines. Instead, they specialise in various forms of talking therapies and/or behavioural therapy. Some of us need to know the theoretical underpinnings of the therapy we are being offered and it's OK to ask.

Many clinicians will reply that their practice is eclectic (not following any one system or method but selecting and using what are considered the best elements of all systems) and empirical (based on practical experience from working with others and constantly evolving rather than scientifically proven). You need to dig deeper than that to really understand their approach.

### Psychodynamic psychotherapy

Psychodynamic psychotherapy is a form of in-depth psychotherapy which has a primary focus on revealing unconscious beliefs and experiences that we are struggling with.

Similar to psychoanalysis but less formal, less intensive and shorter; it is strongly based on the therapeutic relationship.

Some of us are wary of any therapy that centres on these artificial relationships, which are really artifacts of the uneven power balance between therapist and client. Others have no problems with them and flourish under these circumstances.

Psychodynamic psychotherapy puts much weight on what has happened in the past influencing what is happening to us now. For a fuller description see <http://www.minddisorders.com/Ob-Ps/Psychodynamic-psychotherapy.html>

### Humanistic therapy

Humanistic therapy applies a more holistic approach to understanding people based on the social context of their lives. It is most concerned with what is happening now rather than what happened in the past.

The humanistic approach has been criticised for being insufficiently political – still continuing to "help the person" rather than locating problems in the fabric of society.

Some of the humanistic approaches include gestalt therapy, holistic health, encounter groups, sensitivity training, family therapies, self-help, and co-counselling. For a fuller description see <http://www.cefocusing.com/pdf/2F1eExperientialFocusingTherapyAUnifyingHumanisticTherapy.pdf>

### Cognitive behaviour therapy (CBT)

CBT is an umbrella term covering several different approaches that are based on the theory that how we think (cognition), how we feel (emotion), and how we act (behaviour) are related and interact together in complex ways.

In this perspective, it is assumed that some of the ways we interpret the world lead to emotions that, in turn, contribute to 'behaviours' that we find hard to live with, or that others find hard to live with, or coping mechanisms that no longer work.

Some of us get a huge amount out of CBT approaches because they are practical, focused on our issues today and we can easily see what is working and what is not. Others feel patronised because we can 'see through' the therapy and feel manipulated.

Unlike other forms of therapy, CBT lends itself to 'easy evaluation' which provides an 'evidence base' (*Hey! This really works!*) that endears it to 'the scientists' lurking in some clinical psychologists' heads, not to mention bureaucrats. As people with real life experience we are not always so sure. It's easy to say that 'we're better' when we're not really (and we often do).

### **Systems or family therapy**

Systems or family therapy emphasises that family relationships are important for psychological health. The central focus is on interpersonal dynamics, especially in terms of how change in one person will affect the entire family dynamic.

Some people diagnosed with 'mental illness' have got things out of family therapy, partly because it gives them a formal opportunity to be heard. Others can find family therapy excruciating. Perhaps this is due to the inexperience, attitude or lack of skills of the therapist but too often it involves the person with a mental illness diagnosis being expected to hold all the pathology for the whole family.

### **Other therapeutic approaches and perspectives**

We don't have room in this booklet to explore all the different types of approaches that clinical psychologists use, but others include: existential psychotherapy; postmodern psychology; transpersonal psychology; multicultural approaches; feminist approaches; and positive psychology.

### **Case management**

In Victoria clinical psychologists work as 'case managers'. As discussed in the chapter on case managers, other case managers come from the fields of psychiatric nursing, social work and occupational therapy.

Some clinicians resent the case management role because they are unable to utilise the clinical skills they so prize. Clinical psychologists have been loudest in voicing their frustrations with this. Sometimes this frustration plays itself out in their relationships with the people they 'case manage'.

Recently there has been a quiet turn on the wheel of evolutionary policy in Victoria, as behavioural techniques have crept back into popularity. Even more recently psychotherapy is returning for the first time since the First National Mental Health Strategy in 1993.

That strategy put economic pressure on the states and territories to privilege 'serious mental illness' and provide intensive case management to 'the most serious' patients (a term challenged by many consumers). At that time psychotherapists either left the system and moved to private practice. A whole generation of psychotherapists were lost to the public mental health system. Others unhappily agreed to become case managers.

## **The therapeutic relationship**

As with psychiatrists, there can be an enormous chasm between the power of the clinical psychologist and 'their' clients. The relationship can be strange and lop-sided.

Clinical psychologists have a good theoretical grasp on concepts to do with interpersonal interactions but are less well informed about issues to do with social control and interpersonal power. The relationship tends to take place on the therapist's terms; in her rooms, at a time that is convenient to her, with her privy to the theory and practice that we are often ignorant about, with notes being taken that we don't get to see, the clock located for only one set of eyes, and so on.

The real risk of clinical relationships is that one person will hold all the pathology and the other person (the therapist) will be granted, by her status, all the mental health. We all know deep down that this is impossible.

For these reasons it is a good idea to find out as much as you can about your psychologist's perspectives, approaches, and ways of working. We are entitled to do whatever we can to make this relationship work for us without having such attempts pathologised (though if you don't want to know, that's OK too).

The reply we get from a clinical psychologist about their style of practice will depend on many factors. These include whether the clinician sees it as in our interest to know, and whether she is a good communicator. Even if you get no clear answer, the style of response will tell you a lot about the psychologist.

Clinical psychologists must be registered (see the section on Accreditation & Registration). They should have their certificate of registration signed and dated and displayed in their room but you can check their registration anyway at <http://www.psychologyboard.gov.au/>. Remember that registration in itself does not guarantee a practice that is ethical by the standards of consumers or clients.

If you have a complaint about a psychologist it should be directed to the Psychology Board of Australia or the Australian Psychological Society. Don't forget, however, that the APS's primary role is to represent practitioners. It does have an important and honoured role of maintaining the standard of psychological practice but it is not a neutral arbiter.

### **Government rebates**

If you are eligible you can receive up to 16 counselling or psychological sessions per year, or 50 sessions a year if your GP can make a good case that your needs are great (in reality, few qualify for this).

Rebates for these services are available to patients with a 'mental disorder' who have been referred by a GP or psychiatrist.

See the section titled 'Money Matters' for more on this.

## \* Counsellors and Counselling Psychologists

**Thera-peutic: noun** Sometimes it takes a very long time to get from the 'Terror' to the 'Phew-tic'.

*2013 MadQuarry Dictionary entry*

'Mental illness' is a hard slog. Many people diagnosed with 'mental illness' have life issues stemming from the social, psychological and pragmatic impact of chronic illness. This is the realm of the counsellor.

Counsellors come from a number of professions and specialise in a myriad of fields that crisscross the paths of many people, not just those of us who have been diagnosed with a 'mental illness'. Some of the specialist areas include: dietary, drought, infertility, family, offender, grief, rehabilitation, financial, victims of crime, relationships, suicide, children's health, abuse, trauma, veterans and veteran's family, gay and lesbian, positive (HIV and Hep C), carers, and adoption.

Some counselling services are provided free of charge, or for a small fee, by charitable organisations, local government, neighbourhood houses, disability organisations and employment services. However, generally, these services are means tested or provided free only for those who are on a disability support and/or aged pension, unemployment benefits, or some other benefit.

It can be hard to find services. You can try doing an internet search, or approach some of the organisations that may be involved in providing such services. These include local government agencies, not-for-profit agencies such as Anglicare, Wesley City Mission, Centrecare, and many smaller organisations. Most of the church organisations try to provide support for people in need regardless of their religious affiliation. Note, though, that these services are usually in demand, short term and goal oriented.

Outside of those speciality areas, the best way to find a counsellor is through word of mouth or by contacting one of the professional organisations that oversee counsellors; they should be able to give you the names of counsellors in your area.

The Australian Counsellors Association (ACA) has a National Public Register of Counsellors – visit <http://www.theaca.net.au/>, phone 1300 784 333 or email [aca@theaca.net.au](mailto:aca@theaca.net.au) – but sometimes it is more efficient to look up on the internet the professional body for the particular group of counsellors you are seeking. For example, financial counsellors in Victoria have a free call number (1300 558 181). Not all groups will have a central registry.

### Specialists in their own discipline

Some people think of counsellors as the least qualified and the least skilled arm of the personal intervention professions, perhaps detecting a lowlier status than, say, psychiatrists. But it's important to understand that counsellors' relatively poor status in the clinicians' pecking order does not translate into practical skills.

The reality is that the different professional groups do different things. Many counsellors are very successful at helping us with specific problems.

On the other hand, we may have a longer, more global, intense relationship with a clinical psychologist (depending on their approach) and psychiatrists serve a different purpose again, placing an emphasis on biology and the brain. These are different roles rather than more or less important ones

### Counselling psychologists

Counselling psychologists are different from clinical psychologists in that their qualifications set them up to provide support/advice/testing/skills improvement in many areas.

They are not primarily pathology focussed.

### General practitioners

There is a core group of GPs in Victoria comprising people who have post graduate qualifications in counselling or family counselling. This allows them not only to practice as a counsellor but also to receive rebates through Medicare. This is one avenue through which the cost of counselling can be dramatically reduced.

Every procedure a doctor performs, whether it is a consultation or anaesthesia, is monitored by Medicare with an 'item number'. The item number dictates which type of clinician is permitted to perform/claim and the scheduled fee (see the section on 'Money Matters' for more on this).

In the case of GPs running a counselling practice or doing some counselling work, the only item number they can use is for a long consultation. Unfortunately, the way Medicare is geared there are financial incentives to spend 10 minutes with each patient and charge the standard fee rather than the 40 minutes required for counselling.

Because of this, GPs with counselling practices are difficult to find. One place to try would be the Royal Australian College of General Practice (<http://www.racgp.org.au/>), or you could investigate a Medicare Local if there is one in your vicinity.

### Registration of counsellors

As with other professions, there are registration procedures which enable us to clarify the qualifications of counsellors (see the chapter titled 'Accreditation & Registration').

One of the historical criticisms of counselling has been that the diversity contained within the counselling profession has made it difficult to have a unified registration system. Stories abounded of 'Every man and his dog being able to put up a billboard and set himself up as a counsellor'.

These days, we have state and territory boards throughout Australia which make it harder for 'shonky counsellors' to get a foothold. Nonetheless it still makes sense to check a potential counsellor's qualifications.

At a minimum, it's usually in our interests to use a counsellor who is registered with a

recognised professional body such as the Australian Counselling Association (ACA) or the Psychotherapist and Counsellors Federation of Australia (PACFA).

Remember, though, that registration does not guarantee an ethical approach from a client's perspective, or a nice person. For this reason, it can be useful to also seek word-of-mouth recommendations from your peers.

## \* Social Workers

**Promotional Ideation: noun** Repeated and intrusive thoughts of professional promotion which may affect clinical outcomes.

*2013 MadQuarry Dictionary entry*

Social workers have a strong academic background in understanding people within the social contexts of their lives.

From their studies they have learned about social theory and social research. Ideally, their academic and practical preparation also gives them a background in social justice and issues to do with quality of life for those of us who have less.

At a pragmatic level, social workers in a clinical mental health context are trained to assess our social needs and develop systems to make sure people have access to their finances, housing, clean clothes, support from family if we want it, and access to communication. This is the profession that is trained to provide support for home to hospital and hospital to home transitions, for example.

These days, sometimes the work of social workers will overlap with the role of generic case workers, which is why so many social workers end up as case workers in clinical services in Victoria.

One of the interesting things about social workers is that many of us will never cross their path, while others will find that they seem to appear everywhere as we try to find a way through a maze of services (some of which we want and many of which we do not).

Many of the settings in which we encounter social workers have little (or should have little) to do with our 'mental illness'. Often we interact with social work at the time of greatest distress, such as when we are dealing with child protection.

### Qualifications & registration

In order to be a qualified social worker, students need to complete a recognised and registered undergraduate course in social work, generally of four years duration.

Courses in community development do not qualify you as a social worker but much to many consumers' joy the tide has turned and community development is coming back into the social work curriculum.

Many social workers are members of the Australian Association of Social Workers. The AASU promotes the social work profession, oversees ethical and professional standards, and advocates "for the pursuit of social justice and changes to social structures and policies in order to promote social inclusion and redress social disadvantage". It's important for consumers to realise that mental health social workers make up only a small fraction of the total number of social workers working in Australia.

### History

It can be useful for us to understand a bit about where social workers are coming from as without this understanding they can be viewed as little more than a pain in the proverbial; bossy, lacking empathy, trying to make us do things we do not want to do, and even taking our children away from us.

Up until the mid 20th Century social workers were called almoners, describing someone (usually related to organised religions) whose role it was to give goods and money to the poor.

The emergence of the term *social worker* was an attempt by almoners to distance themselves from organised religion and to professionalise. This meant study, a developed job description, qualifications, registration and professional status.

Over the years this new professional power has grown and social workers joined the ranks of clinical groups competing for authority, not only in the mental health sector but across the mainstream health and community sectors as well.

Social work is now undoubtedly seen as a profession with its own body of knowledge, standardised educational qualifications, registration and professional status. Its professional status has been hard won and is vigorously protected by the Australian Association of Social Workers.

The profession fills that space where the consumer's life line crashes into the social world; where our lives, families and 'illness' meet the institutions of the state such as social class, sexual preference, the media, the family, religion, and education.

All of this translates into social workers (like other clinicians) gaining power over those of us whose lives rotate around issues of poverty, homelessness, Centrelink, pensions, the dole, joblessness, hopelessness, issues with child rearing, criminality, racism, ethnicity, drugs, alcohol and 'mental illness'.

### Education & training

Social work education can differ enormously from school to school.

During initial university preparation, some schools run a very structural study in critical sociology. In such a school, social workers look in depth at the institutions of society and the way they so tightly control how we live and relate, endowing some of us with more



than our fair share of economic, social and educational capital, and leaving others severely disadvantaged.

Social workers trained in this school will often see the central tenet of their practice as social justice and will understand how they contribute to the injustice that their 'clients' experience. The individual is not so much the central point but rather the community, the school, the town. So their interest is in systemic advocacy. This is a politically idealist approach.

Other schools of social work concentrate on traditional interpersonal work with people who seek help to solve social problems in their lives.

Within mental health, the academic schools which follow a more classical approach produce more conservative graduates with a different set of competencies and expectations. This is an area dominated by the medical model and all that this entails, including the traditional orthodoxy of diagnosis, treatment, and prognosis.

Training for social workers is a combination of generic theory and practice followed by short periods of time learning about specific areas of work, such as social work in mental health or social work in child protection.

Social work education does not spend a lot of time concentrating on mental health social work, with some schools still only giving a two-week elective on mental health. It's doubtful that competency can emerge from this. Of course, most of the real learning is done on the job.

One of the things graduating social workers learn is the hierarchy within mental health workforces. All the bravado of the professionalised social worker breaks down in the reflection of the power of psychiatrists.

## Good practice/bad practice

Social workers work with individuals and families with the intent of improving the capacity of 'the neediest' to connect with society or protect vulnerable children or 'empower' people.

Very often the people who enter social work do so with good intentions but uninformed views about some of the fundamental concepts that will inform their future practice. There is a social work adage that they don't do things *for* people; rather they enable people to do things for themselves. Consumers know that this is very rarely true and, despite their claims to the contrary, that social workers are often disempowering.

Some of this is revealed in the language used – the words 'case management', for example. How can we possibly be 'empowered' and 'managed' by social workers at the same time?

Although social workers, at their best, can be a wonderful resource, the sanctions they control scare many of us into pretending we are doing things we are not.

If we or our family are working with a social worker from any jurisdiction we might expect four things:

1. **Competency.** We need our social workers to know all the systems they crisscross intimately. We hope they have contacts and understand all the laws, regulations and precedents that will affect our lives and those of our families. Unfortunately, particularly in some of the most difficult areas, there is extraordinary level of turnover of staff. Experienced social workers often choose to move on from the most challenging environments, leaving the very difficult environments to young clinicians who are often out of their depth, despite professional supervision.
2. **Communication** that is both good and fair. We wish it wouldn't happen but we know we will be spoken about behind our backs. But we would appreciate someone letting us know when plans are being made for us. We rely on social workers to push through the jargon and tell us the truth. It's also important that our Advance Directives are recorded, kept competently filed, and utilised when we ask for that.
3. **Understanding power inequity.** A common consumer saying about social workers is, "There goes the pink twinset brigade." This might be a bit naughty (not to mention bad for mutual respect) but it does help to provide us with some precious insight into power. It is a comment about social class, privilege and the fact that our social workers usually don't come from the same social class as many of their clients.
4. **Passion.** Sometimes the social workers who are admired most are those who go in to battle for us, who push the boundaries of professionalism, who talk and think and act just a little bit like us, who recognise and fight against injustice in all its guises.

Whenever consumers organise consumer-run educational opportunities for clinicians and trainees, the groups that seem to consistently understand why it's vital are invariably occupational therapists, social workers and psychiatric nurses.

This gives us hope for the future!

It's also worth noting that social work academics routinely ask consumers to co-teach entire social work units in mental health. We get good feedback from undergraduate social work students who simply love to talk about the issues of greatest importance to both them and us.

However, there is a process of cynicism and a tendency towards institutional ways of behaving that seems to pervade new social workers once they start work. This can have a devastating effect on both their own job satisfaction and their effectiveness. A lack of political knowledge about how large organisations work, combined with a clash of ideals seems to leave new social workers critically questioning what practice is all about and fomenting discontent.

Despite this, consumers do encounter some extraordinary, reflective, sensitive, caring, questioning, sharing social workers, many of whom are working on educating the next generation of clinicians.

Our support goes out to these people because, particularly the public system, it is a tough place to survive and thrive whilst still maintaining the gentleness and generosity we also admire.



## Complaints

The Australian Association of Social Workers (see the chapter titled 'Accreditation & Registration') can investigate complaints against a member, though it's worth noting that that it is not compulsory for everyone practicing as a social worker to be a member.

Associations and colleges representing clinicians in mental health, including the AASW, are generally as anxious to get rid of rogue practitioners as we are – though we might just have a very different definition of rogue!

See the section titled 'Making a Complaint' for more about this.

## Rebates

Consumers with a GP referral may be eligible for counselling by social workers under the Federal Government's Better Access Scheme. Social workers participating in this scheme are required to provide short-term, goal-oriented, focussed personal resources for us.

It's important for anyone contemplating counselling from a private social worker, or anyone being advised by a GP to get some social work counselling, to gain a more detailed understanding of the possibilities and restrictions that apply. Some further information about Medicare rebates is provided in the section titled 'Money Matters'.

## \* Occupational Therapists

**Occupational Therapists:** *noun* Rustic autumnal homemade skirts and leggings in winter.

*2013 MadQuarry Dictionary entry*

Occupational Therapy (OT) is perhaps the least understood of all of the clinical groups working in mental health. People find it easier to understand occupational therapy in the context of physical health, where providing people with occupations that rehabilitate limbs, for example, makes sense. But what does an OT do in mental health and why?

OTs work on the basis that everyone needs meaningful *occupation* (in this context we are talking about *activity*, not paid work necessarily) to optimise wellbeing.

Traditionally OTs have often been teased as contributing no more to mental health services than a diversion ("basket weaving"). This is unfair. Many people with experiences of acute psychiatric hospitals speak highly of the input of respectful OTs.

Over the past decade many OTs have also formed successful and promising working

partnerships with consumer consultants.

OTs are interested in the social and environmental factors that exclude us (people who have been diagnosed with 'mental illness') from some of the vital parts of community life.

Within a hospital setting, OTs are often found running 'The Program'. This means that, within the constraints of their resources – including time resources – they design 'activities' for us to be involved in. Sometimes these are thought of as 'therapy' and sometimes not. Sometimes they are made compulsory and sometimes not. Sometimes these can be run really well and provide a great learning opportunity, but if poorly run by someone with an unfortunate attitude, it can feel like a kindergarten art class. This is definitely not OK and we shouldn't have to put up with it.

Like social workers, the new community provision of mental health has cast OTs into different roles. Many are now working as 'case managers' in clinical settings and key workers in the non-government sector.

Although consumers often heap praise on the contribution of an OT to their healing it is, to some extent, the forgotten profession in mental health.

## Qualifications & registration

Most of the occupational therapists we will come across in the system will have trained for four years to achieve a Bachelor of Occupational Therapy. A smaller number will have done extra study and may have a Masters in Occupational Therapy or a Doctorate in Occupational Therapy.

Registration of all occupational therapists in Australia is undertaken by the Australian Association of Occupational Therapists (AAOT – [www.otaus.com.au](http://www.otaus.com.au)). You can check that an OT's registration is correct and up to date through the AAOT.

For more information on registration and professional bodies see the section titled 'Accreditation & Registration'.

## The role of occupational therapists

The role of OTs is defined by the Australian Association of Occupational Therapists ([www.ausot.com.au/](http://www.ausot.com.au/)) as:

*... promoting health and wellbeing through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by enabling people to do things that will enhance their ability to participate or by modifying the environment to better support participation.*

As mentioned above, many people rather dismissively equate occupational therapy with basket weaving. There are probably as many jokes about OTs and basket weaving as there are about social workers and Rottweilers!

The way that we experience OT activities in hospital settings depends heavily on who we are as people, with all the individuality this implies, and who the OT is, with all the individuality that implies as well.

Many consumers say that OTs are their favourite clinicians. Often they find they are able to have conversations with an OT that they could not possibly have with some of the other clinicians. (Note, though, that OTs still work as part of 'The Team', and thus may report what you say to others. See the section titled 'Privacy, Secrecy and Confidentiality' for more on this topic.)

Many consumers say that they find the 'occupations' OTs bring to the ward pleasurable, and that they also fill in long hours of boredom.

Other consumers hate 'community ward meetings', or anything that's compulsory, or anything that poses as 'therapy', or anything that seems childish or amateurish or patronising.

Regardless of whether we are in hospital or not, we have a right to be in our bedroom during the day if we want to, without being "told off". After all, we are supposedly sick!

We also (in theory, at least) have a right to withdraw with honour from an activity that feels unsafe or stupid.

Some consumers in the private system get back-up letters from their psychiatrists designed to excuse them from programs. We can all ask for this but not all of us will have such obliging psychiatrists.

Some of us use the term, 'therapised' to describe the awfulness of being programmed into oblivion. This is more common in private hospitals where the arrangements with health insurance funds and the bodies that register and carry out inspections dictate the amount of programming needed for accreditation. Here, OTs (along with clinical psychologists), often against their instincts, are required to provide 'activities' which are, at best, banal, at the behest of agencies who know nothing about us.

Of course, none of these things represents every consumer's relationship with occupational therapy, and many of the objections can in any case be overcome by a highly capable OT. In addition, consumers who use private hospitals seem to have a very different reaction to well-equipped art rooms supervised by OTs. Where there is freedom of movement, mutual respect in relationship and choice of activity, great strides can be made towards our emotional health.

### Strange Language

Occupational therapists have a tendency to use words in very strange ways at times, perhaps as part of efforts to bolster their status in comparison to other clinical groups.

As consumers we do not blame them. We know there is a hierarchy of professions within mental health services and we observe that some nurses and OTs (undeservedly) do not have the same authority as other groups.

Nonetheless, we are allowed to laugh when people are thinking seriously about the patients' laundry getting signage which heralds: the *Room For the Practice of the Tasks of Everyday Living!*

### Status and hierarchy

Many OTs are keen to point out that they are different from, and have been trained differently to, other clinicians working in mental health.

To some extent this is true. Some consumer consultants working in clinical services in Victoria have reported that the person who is most supportive of their work is the OT. There are also reports that OTs and consumer consultants have set up programs in acute and other settings which they run together. This is a good model and should encourage attendance.

On the other hand, OTs are often not as different from the other clinical groups as they would like us to believe. Pragmatism is often the rule of thumb for these clinicians and sometimes this can come at the cost of developing a real understanding of the political parameters in which all psychiatric services operate.

The word 'political' refers here to power. In acute hospital settings, for example, OTs might not see themselves as having that much power in the scheme of things (not helped by the fact that it is a strongly female gendered workforce with limited political sensibilities) but compared to patients they have a lot.

If they are fair dinkum about their claim that they are different from other clinicians and their consumer orientation is central to their practice, we need to be able to rely on OTs to cease crying institutional impotence and try to join us politically. It's great to have a listening clinician but it's even better to have a listening-action one.

### Complaints

If we wish to make a complaint about unethical or unprofessional behaviour by an OT, generally we will be advised that our first point of contact should be the director of clinical services within the organisation where the behaviour took place.

Some of us feel that that is bound to be biased as the organisation closes ranks, although it can be a useful place to start.

Complaints can also be addressed to the Australian Association of Occupational Therapists ([www.otausvic.com.au](http://www.otausvic.com.au) – see the section titled 'Accreditation & Registration').

See the section titled 'Making a Complaint' for more on this topic.

## Rebates

Some Medicare-funded counselling under the Better Outcomes in Health Initiative can be provided by OTs who are registered counsellors, though only a very restricted range of therapies are allowed.

OTs are funded to provide Focussed Psychological Strategies – whatever this is. No one, including the majority of OTs, seems to have any idea.

See the chapter titled 'Money Matters' for more on this topic.

## \* Student Clinicians

**Medical Student: plural, noun** Scotch College, Methodist Ladies College, Camberwell Grammar, Caulfield Grammar, The Scots School, Xavier, Kings School & Fintona Girls Grammar...

*2013 MadQuarry Dictionary entry*

All of us who use public mental health services come across students. Student social workers, doctors, psychotherapists, psychologists, psychiatric nurses and occupational therapists all have to learn their trade by practicing their craft.

What is important for us is how these beginner clinicians relate to us, learn from us, address us, listen to us, talk with (and not at) us, and learn to work with other clinical groups in teams of equally skilful and mutually respected people, not competitive individuals from different clinical camps.

## Education in universities

Many of us have had the opportunity to work with student clinicians in university settings.

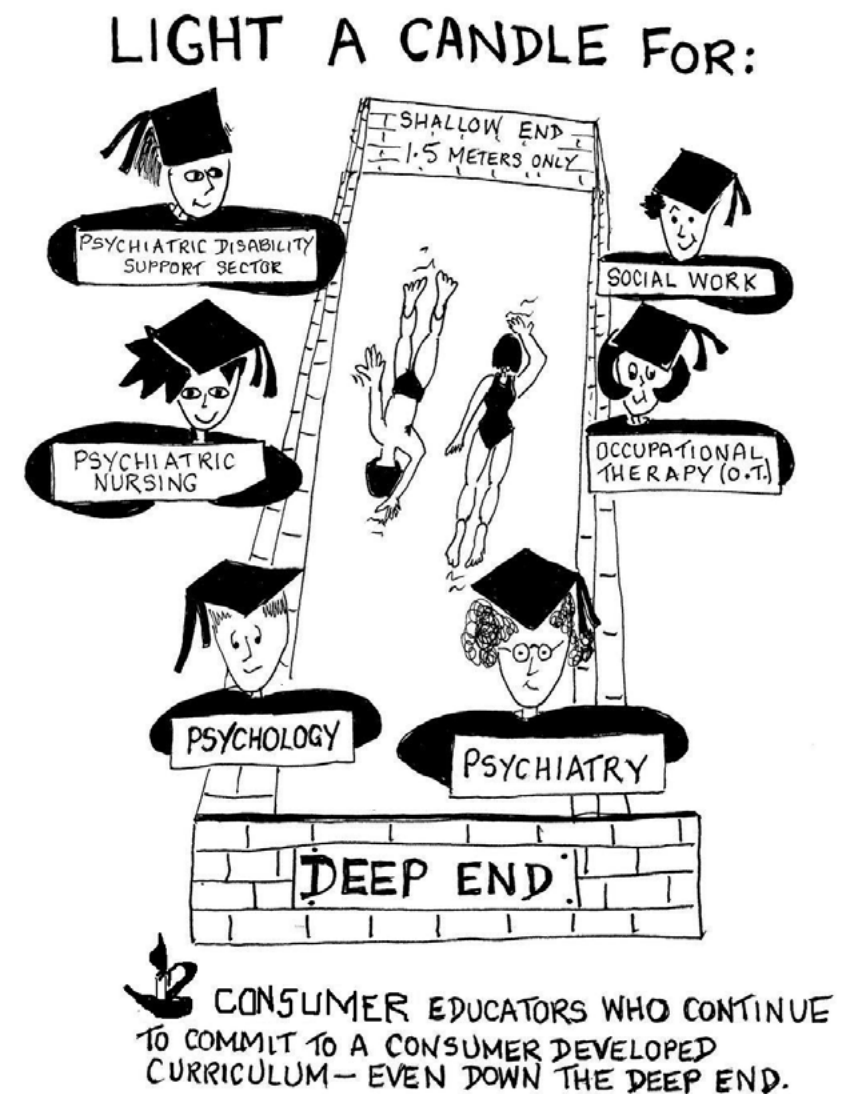
There's a lot to be learnt by observing which faculties invite us to be part of teaching programs and which do not, as well as how our participation is perceived and understood.

There are courses in social work and occupational therapy around Australia where consumers are involved in joint running of the mental health component of the course. By this, we mean consumers help to plan the course, make sure consumer perspective texts are on the compulsory reading list, co-teach, and bring in other consumers in an empowered way to use their stories as teaching methods.

The problem with both of these disciplines, however, is the competition for student time. The allotment for the mental health component can sometimes be miserable.

In nursing, an interesting model comes from the University of Melbourne, which has a consumer academic in situ in its Department of Nursing. Although this puts a strain on the incumbent (everyone wants a piece of her!) this is a fantastic model as the consumer academic is heavily involved with all students. She is also involved in the research program, and has introduced many other consumers (who are paid sound academic salaries) to advise her program, and as research colleagues and sessional staff.

These are the sorts of measures that move consumer educators from tokenistic to real. They make a significant difference to students and we are often told when we are in hospital by staff members that this component of the course was very important.



On the other side of the equation, the introduction of consumer educators into the education of psychologists and medical students is piecemeal and often unsatisfactory. And the general feeling amongst consumer educators is that clinical psychology is a hard nut to crack. We have unfortunately had very limited success in influencing the training of post graduate clinical or counselling psychologists.

It's at the peril of ongoing practice that consumer educators continue to be underutilised. What we would like to see is consumer educators in all disciplines right through every course. If we are going to be the fodder for the education of clinicians then we must also be a fundamentally important part of the education system that creates these clinicians.

### **The right to decline**

We may encounter students on placement in a range of settings, including public psychiatric units, public hospital emergency departments, private hospitals, on crisis, assessment and treatment (CAT) teams, as well as in places like Centrelink and child protection and services for older people, children and youth.

It is important to know that we do not have to allow students to examine us, ask us questions nor see our records if we do not want them to. It is our choice.

The problem with this is that the authority and discourse of medicine has a lot more power than a lone patient. In most instances we say 'yes' to student involvement when we may mean 'no'. Many of us find ourselves agreeing to students being involved in almost everything when, really, we would rather they were not.

### **Registrars and medical officers**

It's worth noting that all medical officers and registrars are students; they are no different, in principle, than any other students we come across in an acute unit or a community mental health service.

It's easy for us to forget this because these students have a disproportionate amount of power in relation to their career stage. The reasons for this are twofold:

1. Registrars are qualified doctors so their student status is often viewed a bit differently (especially when they forget to tell patients they are not qualified psychiatrists!); and
2. Medical practitioners, fully trained or not, tend to command a lot of status in the field of health and in society as a whole.

### **Social work, psychiatric nursing & occupational therapist students**

These students also carry out placements in the field but they are organised differently.

Usually a student is placed with a clinician for a period of time. As a patient/client you will be introduced to the student and a request will be made offering you

the opportunity to do things with the student, both with and without the clinical supervisor.

Many of us are less fearful of these types of clinicians and feel more able to refuse if we don't want students to be involved.

Nonetheless all clinicians have power over us and sometimes we need to remind ourselves that it's our choice whether we wish to do something or not.

### **Consumer experiences with students**

People's experiences with students vary enormously. Because we are human just like anyone else we have very different experiences that leave us enthused or make us angry.

One consumer writer describes how the student nurses (not psychiatric student nurses but ordinary student nurses) saved her from trying to kill herself in a public psychiatric hospital. She describes their beautiful innocent conversations, how they didn't hold in their bodies the judgement and superiority seen in other clinicians, and how this enabled her to speak about a terrible thing she had told no one about before.

Of course, clinicians might argue that students just have more time. This may be so but there is a clear message that listening is as important as, or even more important than, observation or constant scrutiny.

Most consumers would like to help students to become more confident (and competent) and many of us do offer a helping hand. This is sometimes appreciated and sometime not.

This applies even when we are in hospital because the students are the closest people to us in terms of institutional power (or lack thereof).

It's often easier to talk and share with students than other clinicians, and to be authoritative about the things we know more about than they do because of our lived experience. Be careful, though, because students remain part of 'The Team' and all things of import that we say will be reported back (see the section titled 'Privacy, Secrecy and Confidentiality' for more on this).

Not all students are patient, interested observers. Many consumers report experiences with students who seem to have bypassed the questioning, reflective, tentative stage in favour of impressing the visiting academics who will grade them and following the score card of the clinician to whom they are apprenticed.

### **Complaints**

If we are on the end of hurtful, damaging or disrespectful practice by either a student or their supervisor, we can complain.

At a basic level, you might just say, "I don't want that student any more" and the service is obliged to remove them from your team. This applies to everyone, even those of us who are being held under the Mental Health Act. We do at least have



some rights, even if we have to be careful about how we use them.

If you have any trouble, ask to see the unit manager or head nurse.

See the section titled 'Making a Complaint' for more on this.

### Stories, voyeurism and being 'unheard'

Some consumers love students coming around. This is especially so in public hospital settings where everybody is bored. A nice natter with a student can be something to look forward to.

Many people with 'mental illness' are invisible in our society. People are lonely, treated disrespectfully, never have opportunities to share their lives with others and are eager to find someone who will listen. People want to share their stories and many students are genuinely interested and often reciprocate in ways that change the dynamic and make the experience one that the consumer looks forward to repeating.

There is an innocence in this; however, that can be manipulated by 'the system'. A minority of students engage in ways that have more to do with voyeurism than with our health.

Our story, in its whole, is special to us. It is who we are. It's the most important thing in our lives. But students in all disciplines are being taught to filter our stories in particular ways depending on the discipline. As we tell a whole magic narrative, students are getting better and better at not listening to it in many settings. They are being taught that they have to key in to specific information that they need, to block out the wholeness. And rarely are we told that that's what's being done.

Students will often be sent out from the university with various assignments they have to complete while on their placement – some of us truly feel sorry for those who are trying, often in vain, to get volunteers to help them complete some task or other. This is, for some of us, one area where we can easily step up, mainly so they can finish the thing. They will be very grateful for our involvement and in the majority of cases.

Helping student clinicians in their workplace practicum remains one of those realities that will continue to influence our experience of care. Some of us will find it interesting, challenging, enjoyable and a good thing to make long days go faster, whilst others will avoid it and condemn it as work for which they are not paid. Either position is acceptable and neither should attract consequences that make life even harder for anyone involved.

### Letter to a 4th year medical student (abridged)

*The letter on the following page has been written by a consumer to her nephew, a 4th year medical student on psychiatry rotation. (All identifying details have been changed.)*

Dear Sam,

### 10 Challenges from Your Favourite Aunt

1. **Language:** Try to make a mental note every time the following terms are used about someone (either verbally or in writing). The list is endless but it includes terms like 'manipulative'; 'attention seeking'; 'venting'; 'lacking insight'; 'difficult'; "just behavioural"; 'non-compliant'. *Think about yourself being called these things.*
2. **Diagnostic and Statistical Manual:** Now to the the DSM-iv (soon to become DSM-v) bible for diagnosis. Interrogate it. Challenge it. Non-aligned? Drug companies? Who compiles it? What actually is a 'mental illness'? How scientific is it really?
3. **Learning from 'patients':** Go on your own and talk to someone on the ward or in the clinic, not with the intention of diagnosing them. This is about recognising what you can learn from them. Start with something like... *"I am a medical student and I know little about psychiatry, what can you teach me?"*
4. **Professionalism:** What does it mean 'to care for someone' and why would this term be used interchangeably in psychiatry with the phrase, 'to manage someone'?
5. **Boundaries:** Who do 'boundaries' really protect – the doctor or the patient? For many of us the most helpful and healing clinical practice is seen by some clinicians as almost 'unprofessional'. Why?
6. **Culture carriers:** Sam, I entrust you with a mission to be a 'culture carrier' of thoughtful practice to other medical students. A culture carrier acts, within their own limitations of authority, to change the way those they work with treat us. By simply not joining in a derogatory joke much can be achieved.
7. **Patient documentation:** If you have had the privilege to see intimate records written about us did it worry you that our secrets were shared with you, a student, a person we didn't even know? Was there a moment of voyeurism, of fascination with the bizarre, of forgetting that the medical story in front of you was actually a person?
8. **'Patients' working for services:** Most public mental health services in Australia now employ people with 'mental illness'. They are called consumers – not patients. My challenge is that you try and make the time to meet with consumer consultants and genuinely seek their counsel.
9. **Duty of Care:** 'Duty of Care' is a legal responsibility for doctors. However it can lead to doctors practising against litigation rather than for the patient. We use the term 'Dignity of Risk'. I would like you to ponder this term.
10. **Keep on fighting for justice:** Sam, darling, too few doctors are driven by social imperatives. I am extremely proud of you. My final challenge is to urge you to develop a vision of 'doctors for social change' and give it to me for Christmas.

All my love, Aunty Jane



## \* Two Hats

**Whistleblowing: verb** The shrill cry of those who can no longer bear the dissonance between what they learnt as an undergraduate, what they experience as consumers and what they see in practice.

*2013 MadQuarry Dictionary entry*

'Two Hats' is a term we have chosen to describe clinicians who also live with a 'mental illness'.

In the community, and within the mental health sector, we construct a false reality that there are two discreet groups: (1) clinicians and (2) 'patients'/'clients'. Despite the ongoing public message that "one in five people has a mental illness," there is an enduring myth that clinicians couldn't possibly be diagnosed with 'mental illness'.

Simple mathematics shows that there must be many clinicians working in mental health, child 'protection', Centrelink and other services who do have 'mental illness'.

### Two Hats and consumer workers

Over the last decade there has been an escalation in the number of consumers employed in mental health services, both non-government and clinical, around Australia.

These have been working in advocacy positions, as consumer consultants, Personal Helpers and Mentors (PHAMs) and now, increasingly, in administrative positions. In these jobs people are employed precisely because they do have a diagnosis of 'mental illness'. They are 'out' by definition.

A proportion of consumer workers are clinicians by training and sometimes by passion but they are not employed to be clinicians – in fact, quite the opposite. They are employed to not be clinicians.

This is a hard position to occupy, especially when many people are desperate to have the social status of their clinical authority restored.

Consumer workers who are clinicians are an increasingly large group whose complex needs are presently under-resourced.

However consumer workers who happen to be clinicians are not the group we mean when we refer to 'Two Hats'.

### Two Hats coming out

Going public about our consumer status when we are working in clinical services as a 'clinician' is not an easy decision. It's a sad fact that some of the worst discrimination comes from within the mental health sector.

It is naïve to suggest that all our colleagues are discrimination free and that

management won't become super vigilant.

Some of us find ourselves working in services that have policies that silence us. It is particularly galling to be forced to be silent when we know that the knowledge we gain by having 'been there, done that' is what drives everything we do in our practice. Sometimes the system is a long way behind where we are in progressive thinking.

Unfortunately we must remember that we are employed as a clinician and our employer has a legitimate say in deciding policy about self exposure. Silence is necessary for some if they want to maintain their employment.

### Not coming out

There are clinicians who choose to be very private about their 'mental illness' status. The enormous pressure to conform to stereotypes of 'upstanding citizens' and 'community leaders' means that as a general rule choosing to come out is not an option for many clinicians.

As soon as we decide to be honest with our employer about our 'mental illness' we are open to our colleagues diagnosing us, offering treatment and telling us what their medical knowledge dictates we should do. This is inappropriate even if it is an effort to be helpful. Most of us have our own arrangements for 'treatment'. They are not at work.

We know of doctors with 'mental illness' who have 'lost it' at work. They have lost their licence to practise and when reinstated many years later and after a fight have found themselves with many pages of conditions attached to their registration by the Medical Board.

Coming 'out' and being forced 'out' are very different things. Being forced out is the worst possible way to come out. All of us must respect the privacy of consumer-clinicians who have made it clear that they want a complete break between their work and their personal life, including their experience of 'illness'.

### Coming out later

An interesting phenomenon we have noted over the past few years has been for some famous medical practitioners and commentators 'coming out' to the world as they near the end of their careers. Everyone goes "ooh" and "ahh" and "aren't they brave!"

It's wonderful that such clinicians do this, but many of us would have loved them to have made the move much earlier. It's hard to know whether they would have survived and thrived in their profession if they had done so.

### The view from within

One of the major issues for clinicians who have a 'mental illness' is that as they sit in staff rooms, walk around psychiatric units, listen to their peers, sit in with assessments and listen to registrars they may well hear things that as a consumer they don't like hearing.

What do you do if you wear two hats? In this area it makes no difference whether you are 'out' or not. The pain of watching poor practice is real in either case.

We know of several clinicians with a lived experience of 'mental illness' who simply can't practice because it makes them too angry. This presents a tragic loss for the profession, as well as for the individual clinician concerned.

We also know of people around Australia with lived experience who have become whistleblowers about bad practice. Not all whistleblowers are consumers but many are. Again, they are often forced to live with an unfortunate consequence, which might include losing their job or getting a bad reference for a new job. It's a terrible shame that consumers must become collateral damage when they are simply seeking to provide excellence in service provision.

Other Two Hats enact a 'consumer code of ethics', which may include the valuing of shared meaning so greatly that they do speak to individual consumer/patients from their own experience.

If found out, a decision to stick with the consumer ethical code can cause angst in the top echelon of clinical management, with disclosure to patients being seen as inappropriate and unprofessional. Two Hats have the unenviable task of balancing two competing codes of ethics and sometimes no one is pleased.

### **Student clinicians with Two Hats**

Frequently clinical students are relieved to hear us tell 'their story', 'their secret', and they 'come out' in class. This is very tricky, especially when the student is young. It's not always safe to tell your story for the first time in public to a group of clinical peers.

Many young, enthusiastic and idealistic students are reaching for ways they can make the system better for themselves and others like them. To some extent they are naïve and vulnerable.

In practise placements many academically gifted Two Hats students come tragically unstuck. It can be galling for a student to find her/himself in a situation where their supervisor reeks of cynicism.

Students don't have the authority to take on the system ... yet. The priority here must be to stay attached to consumer politics if you can and keep documentation of all the things that upset you. This will remind you of your idealism later on when the insidious process of institutionalised pique starts to lure you into the fold.

Consumers tell us that there are some clinicians with lived experience of 'mental illness' whose own practice is less than ideal (or even terrible).

This is not so hard to believe. It happens in other areas of life as well, where people try to distance themselves from a horrible experience. Some of us behave in ways that are the opposite to what's good – from a consumer perspective – because we so much want to be 'A Professional' and get away as far as we can from the embarrassment of our 'mental illness'.

## **SECTION 3: Getting What You Need**

## \* How Do I Find Help?

**Finding a clinician: verb** “Has anyone around here seen a clinician?” asked Pooh. “No, not me”, said Tigger. “Not me either,” said Piglet and Eeyore at the same time. “Shall we look?” thought Pooh, but just before he could have a big thought Tigger jumped out the window. “Come on,” Tigger said, “Let’s run.” They all jumped out of the window searching for a honey-based solution that would suit Pooh just fine.

*2013 MadQuarry Dictionary entry*



It's so hard for any of us to know whether what we are experiencing is 'just normal stress' or something more than this.

For the majority of us our first step towards getting help is a very difficult one. Some of us are ashamed that we seem not to be dealing with our lives better, and others are quite scared about what is happening.

Because of prejudice, many of us have never spoken to anyone about the thoughts, fears and sometimes strange behaviour.

Although it is difficult and may necessitate divulging personal information, it is worth finding someone to work with you to find a therapist. Bad experiences at the

beginning of your journey can harm future relationship building.

Breaking the silence of mental distress can be emancipating. If you can find someone who you trust, and who you know has been on a similar journey, this is even better.

## Public Adult Mental Health Services

The public mental health systems in Victoria are very complex. In brief, the component parts are:

- Child and adolescent services
- Young people's services
- Adult services (aged 16 – 64)
- Aged services.

Within each of these areas there are a number of programs, or parts, that in theory fit together to provide a comprehensive service system. For example, some of the services that come within the Adult Mental Health Services cluster are:

- Acute Psychiatric Services
- Area Mental Health Services (chronic illness)
- PARCs (Prevention and Recovery Care Services)
- Crisis and Assessment Team (CAT Team),
- Mobile Support and Treatment Teams.

The majority of services are provided by Area Mental Health Services, which are geographically focussed. There are also a small number of state-wide services, including a state-wide personality disorder service and a state-wide eating disorder service.

All publicly funded services are free.

Free they might be but available they often are not. Only a tiny minority of people, mainly those who are adjudged to have what is called 'psychotic illness' or very serious forms of 'personality disorders' and 'disorders of mood' can access these services, regardless of whether we are pensioners or on the minimum wage and unable to pay for anything else.

Public services need to get a lot better at acting when consumers don't fit their criteria for service. We often need intensive help, not just phone numbers. Community development practitioners are badly needed here but they are impossible to find.

If you are refused services, take a moment to understand the plight of busy people but then ask again for the help you need. The more of us who do this the more likely it is that conditions might change.

Remember that a refusal to help you might have nothing to do with a service thinking you don't matter, even if it feels that way at the time.

## Community Health Centres

Community Health Centres (CHCs) are geographically defined. Sometimes they employ mental health workers.

It's often easier to get to see a mental health worker in a CHC than in a designated Public Mental Health Service because CHCs' definitions of eligibility are broader. They tend to be services where the social is paramount, where the clinicians can place an emphasis on counselling. They work a little bit like Community Legal Centres – they tend to be cheap, often have a means test requirement (so that those who struggle to pay are not disadvantaged), and operate independently but as part a web of services with similar values and ethics, traditionally around providing services for people fighting all sorts of social ills such as drug addiction, alcohol or gambling addiction, child abuse, trauma and poverty.

The listing at <http://www.health.vic.gov.au/pch/commhealth/directory.htm> may help you to find a CHC near you, or one that specialises in an area of health that affects your life.

## The Bouverie Centre: Victoria's Family Institute

Bouverie may be another option. Affiliated with La Trobe University, Bouverie has many programs designed specifically for families confronting 'mental illness'. The clinicians who work there – frequently clinical psychologists and counselling psychologists – have generally completed qualifications in family therapy.

Like all publicly funded services, money is tight and services are triaged. Nonetheless it is worth making contact. Services are not delegated on the basis of so-called 'serious mental illness'.

See <http://www.bouverie.org.au/>.

## Centres Against Sexual Assault (CASAs)

Centres Against Sexual Assault (CASAs) are but one of the subsidised and responsive possibilities designed to address specific problems that cause deep emotional pain and psychological distress.

Many of the counsellors are counselling psychologists.

Visits to CASAs go really well for some and totally miss the mark for others, but they are there if you need them. This is hard stuff so take a friend with you.

See the Victorian CASA Forum: <http://www.casa.org.au/>

## Veterans Affairs

The Department of Veterans Affairs provides many services to ex-soldiers. Counselling is available by clinical and counselling psychologists.

See here for details: <http://www.dva.gov.au/benefitsAndServices/health/Pages/index.aspx>

## Private services

Other alternatives include counsellors, private psychiatrists, clinical psychologists, occupational therapists, dieticians and social workers. Some of these professions are explored in the preceding chapters.

The Commonwealth Government has made it easier to access many of these clinicians by allowing Medicare rebates for some services. Nonetheless, often the factors that enable or disable our utilisation of services provided by private clinicians are proximity and money. See the section titled 'Money Matters' for more on this.

## It's your journey

It's important to note that you will not be locked into whatever decision you initially make about where and how to access help.

It's in everyone's interests that consumers engage maturely with health professionals and it's your right to make (and to continue to make) independent decisions about what is helpful for you, and what's not.

## \* When We Have No Choice

**Power: noun** Power is always felt by those who don't have it and invisible to those who wield it.

*2013 MadQuarry Dictionary entry*

Having the option of being centrally involved in selecting our own psychiatrist is a human right, but unfortunately too often that's not possible.

## Public psychiatric units

Public psychiatry units are attached to large public hospitals. The movement from stand-alone psychiatric hospitals to units within general hospitals took place predominantly in the early 1990s and was called 'mainstreaming'. The vast majority of these units are locked even though there is a minority of patients within them who are not 'sectioned' (held against our will).

Almost everyone who is admitted to a public psychiatric hospital or uses a public mental health service has no choice about who they see in term of clinicians.

Even if we are a patient of a private psychiatrist, there is usually only minimal contact between them and the clinicians within the public hospital system – usually we are admitted by a different psychiatrist, especially if we are being detained involuntarily.

This is because the Victorian Mental Health Act stipulates a maximum time between when the crisis team detains us and when we are formally assessed by a psychiatrist. So whoever's around has to do.

You will not see your allocated consultant frequently during your hospital stay. The longest opportunity you will have to speak with him/her will be the first conversation you have. He/she will ask you to follow them into a small, sparsely furnished examination room. The registrar will accompany you and the consultant might also ask you if you mind if a student can observe.

This first conversation, which the medical staff call 'getting a history', might feel a bit like a forensic cross-examination to you. This first conversation is the time to present your clinical Advance Directive if you have one. Note, though, that there is no guarantee that they will treat it seriously and many clinicians still don't know what it is.

The consultant will then pass 'the case' (you) on to be 'managed' on a day-to-day basis by their registrar. Again, we have no choice in this. If the registrar is someone who is completely rude and intolerable to us, incompetent or lacking confidence and experience, we can complain to the nurse unit manager that we are unhappy with this doctor-who-is-a-student and say that we need another one. This doesn't guarantee action but it might work if the manager is empathetic, confident, has read our Advance Directive, and has the capacity to shuffle his/her team around.

But with the occasional exception, we get who we get. Most psychiatrists working in public mental health services are:

- consultants working a few sessions a week;
- psychiatrists who are primarily researchers;
- international doctors sharpening up their English skills;
- registrars being rotated around different settings, who have one eye on the unforgiving exams they have to pass in five years' time and the other eye on pleasing and impressing the consultant;
- psychiatrists who have a primary interest in bureaucratic and senior management roles; or
- very dedicated psychiatrists with strong social consciences who choose to work with homeless people, poor people, world weary people and the oppressed.

Even if we did have any sort of choice it would be limited to these groups of people.

## Area Mental Health Services

The majority of people who are committed to a public psychiatric unit also work from an Area Mental Health Service.

There are several ways that we interact with clinicians once we are registered in an Area Mental Health Service, but basically we have no choice about which clinicians do what in relation to our health.

This is no different from public hospitals and services in the area of physical health except for the fact that as soon as you are declared to be an involuntary patient you not only have no choice about the clinicians you are allocated, but you also have no choice about whether you accept clinicians in your life at all.

This gives extraordinary power to clinicians who may or may not earn it and who may or may not abuse it. In this situation a weight of responsibility falls on the 'management team'. It is their responsibility to make sure we are safe from unnecessarily coercive treatment.

## Community Treatment Orders

A Community Treatment Order (CTO) is an order made under the Mental Health Act 1986 (soon to be replaced by the Mental Health Act 2013), which is signed off by the Mental Health Tribunal.

People on such orders have many freedoms taken away even though they are no longer in hospital. Failure to keep the conditions documented in one's CTO results in people being re-sectioned – that is, locked up in hospital again.

Victoria once prided itself on using CTOs to get people out of oppressive regimes in psychiatric hospitals. We led the world but the unfortunate result is that Victoria now has far too many people on CTOs.

Those of us on CTOs have our lives controlled by a team of medically trained 'police' who once were clinicians. What is choice for any of us under such orders? The term that we are being released from hospital '*back into the community*' under a CTO is a euphemism.

Unfortunately there is rarely any choice or opportunity to work with clinicians we believe would suit us, have a good reputation with consumers, or whom we seriously believe will do no further harm. It is pot luck (or pot misfortune).

While there's no doubt that there are many excellent clinicians working in the public sector, and sometimes efforts are made to match a client with the clinician they believe will most aid recovery, this is all too rare.

Unfortunately we have also heard of consumers whose complaints about a particular clinician, a complaint that has merit, has been dismissed as further symptoms of their 'illness'. This is so dangerous for consumers on CTOs because they can be whipped back into the lock-up hospital extremely easily.

## Patients as 'guinea pigs'

Those of us who use public services are in the view finder for clinical trials of 'new drugs' or double blind trials testing things like people's reactions to Vitamin D supplements (or whatever).

We are also in the line of fire for registrars trialling a new way of doing this or that in preparation for their exams.

Sometimes we are 'bagged' by clinicians who are undertaking research in an area that is compatible with our diagnosis and life circumstances.



Although research psychiatrists do observe the requirement to obtain informed consent before doing any research or using our files for research purposes, there are many reasons why many of us say 'yes' to this when we mean 'no'.

These issues have a lot to do with power and relatively little to do with wholesome choice (on a purely practical level, learning to please the most powerful is sometimes crucial for survival).

This is not to say that some people using public services are not pleased and excited about being involved in something that may bring better outcomes for them or others. But it's important to note that you *do not have to take part*.

## The effect of money on choice

The public end of psychiatric practice is skint. Poor people who rely on it never get the choices (or arguing power) that people using private psychiatrists do.

It's not just that choice isn't there to start with, it's also that 'getting better' also works to limit your choices – 'getting better' in public services means something quite different from what it means in private psychiatry; wellness on any level often leads to us losing our service. Many of us learn to sabotage the 'therapeutic' relationship in the vain hope of holding on to the services we have.

Those of us confined to public services by our financial circumstances also get less choice in terms of 'treatments'. Psychiatrists working in the public sector sometimes use cheaper and less effective drugs that have worse side-effects, or use us to trial brand new, untested drugs. While we are asked for consent, in truth we have little 'real' choice about this.

## \* Finding the Right Psychiatrist

**Private Psychiatrist: noun** Publicly funded Private Psychiatrist!

*2013 MadQuarry Dictionary entry*

Finding a psychiatrist in private practice is often fraught, partly because this task usually comes at a time when we are emotionally distressed, but also because it's an area most of us have thought little about until we bang right up against it.

Relationships between doctors and 'ordinary people' have changed since the 1970s. Although there are still many people who choose to take only a small role in the decisions that affect their health care, there are now many of us who want to be active players.

Doctors, including psychiatrists, are beginning to get used to this but many remain sceptical.

## Doctor shopping

The term 'doctor shopping' often has quite negative connotations – some people in the medical field see 'doctor shoppers' as 'bad' people going from doctor to doctor to get medications, or 'dependent' people who seek services they do not need.

For many consumers, however, 'doctor shopping' is about assertively searching for the psychiatrist who has the attributes we are looking for.

Of course, the first step is to decide whether psychiatry is the way we want to go. Then we need to find the best professional relationship we can.

GPs often have a set of specialists to whom they have sent people before. Sometimes they rely on professional reputation, and feedback from patients can also influence their decisions. Sometimes GPs' criteria for making particular referrals are rather rudimentary, such as, "*other patients say she's very nice*". What does this mean in terms of this psychiatrist's practice? Probably not much to us.

We don't have to go with the GP's suggestion. We can do our own research about who we would like to see. GPs react in different ways when we do this. They are generally not used to 'their' patients being involved in making decisions in this way. Some GPs will be grateful for our guidance; some will be threatened.

Sometimes age, gender, social class, culture or life experience leave people with unreserved faith in the information and referrals we are given by general practitioners (GPs). Others no longer have this faith. Neither position is right or wrong. They are just different.

Other places you can go to find some names of psychiatrists include friends and family, consumer/patient organisations, and even Google – internet-based chat rooms may (with care) be a useful place to start your research.

Whichever way we go, we will need to have conversations with our general practitioner about our decision because without a referral from a GP to a psychiatrist we will not be able to claim from Medicare.

## Questions for ourselves

Before you start your search for a psychiatrist, ask yourself some questions:

- What am I looking for?
- Do I understand the difference between a psychiatrist and a clinical psychologist or counsellor; and am I sure it is a psychiatrist who would be the greatest help?
- Have I thought about costs? Can I afford a private psychiatrist? How often could I afford to consult a private psychiatrist?
- Is location important? (Private psychiatrists tend to be located in the more affluent suburbs of Melbourne, although there are few in the western and northern suburbs, and fewer still in rural and regional areas.) Inconvenient location can prove a problem because of frequency of visits but many people

say that if the relationship is a good one, location is secondary. Distance from public transport is worth investigating as well.

- Am I prepared to take medical drugs, and do I understand their unwanted effects, including weight gain?
- Does the person I'm looking for need to have a specialist interest in, for example, childhood trauma?
- Do I want to see someone who has a public profile, and a strong reputation in the field? Do I mind if that impacts on their availability?
- Are there some personal attributes that I favour (remembering this might change in practice but it is a worthwhile exercise anyway)?
- Is the gender of the psychiatrist important?
- How desperate am I? Can I wait for someone who has a long waiting list because they are good?

## Questions about and for them

Once we have a shortlist, it's vital to start with researching some very basic information:

- Is the person properly qualified and registered as a psychiatrist?
- Have there ever been any complaints made about her/him or his/her practice?

You can easily get this information from the Medical Board of Australia ([www.medicalboard.gov.au](http://www.medicalboard.gov.au)).

Next, it's time to ask some questions of and about your psychiatrist. Here are some questions you might want to ask about a psychiatrist to help you assess whether or not they will be a good match for you.

(Of course, you do not have to try to find out about any of this if you don't want to. Some people need to find trust through belief that 'doctor knows best' and this is completely acceptable and may, in some cases, save confusion and extra worry.)

- **Their qualifications** and registrations;
- **Their attitudes towards different therapeutic approaches:** including psychiatric drugs, behavioural therapies, psychoanalytic psychiatry, and any more directive theoretical underpinnings to their practice (particularly if they come from a specific school of thought);
- **Their professional interests:** Do they have any specialties or particular areas of interest (childhood trauma, mood disorders, etc.)?
- **Their recent experiences:** research, clinical, and bureaucratic (also noting how often their professional interests call them away from their practice);
- **Their practice preferences:** Using psychiatric hospitals or avoiding them except as a very last resort? Medications or talking therapies? Weekly visits or much less regular visits?

- **Their fees policy:** Do they have a sliding fee scale? Do they bulk bill people on Disability Support Pensions? Is there room for negotiation? Do you have to pay on the day, or can it go on to Medicare first?
- **Their 'engagement rules':** Some psychiatrists have 'engagement rules' in place. Often these take the form of 'contracts' which we have to sign. They might relate to things like missed appointments, arriving late, provision of telephone advice, payment for writing letters and so on. This is a big turn off to some of us, but for others they offer clarity and certainty. Either way, they can provide an early gauge of the psychiatrist's attitudes.

## A word of warning

It is empowering for many of us to know as much as we can about the psychiatrist who could potentially 'mess with our mind'; however, some very fine practitioners with good work ethics and empathic skills can spit the dummy at being "cross examined" by a patient they hardly know.

Be prepared for the possibility of that reaction before you wade in.

## The therapeutic relationship

Finding the right psychiatrist can sometimes be difficult because the 'clinical relationship' gets entangled with the bare bones of our health decision making.

As a general rule our intuition is not a bad tool.

During the first few visits you will be getting to know the psychiatrist and s/he you. You should start to have some ideas about their personal qualities. Intuitive feelings will usually come before you pick up on skill and practice competence.

You might find someone who on paper looks experienced, has done lots of 'first class' research and is often on the radio. However, face to face this person might be bullish, arrogant and dismissive.

During these first weeks we also start to gain more clarity about what we are looking for, about what we can engage in and what we can't, about definitions of professionalism and ethics and so on.

We are all different. Someone might really be impressed and relieved when the psychiatrist turns up in Blundstones and someone else might find this 'unprofessional'. It's all about finding a relationship that is right *for you*.

Sometimes psychiatrists use eclectic practices that are hard to describe. It is extremely difficult to give informed consent to something that can't be explained to you; but this doesn't necessarily mean it isn't any good.

What clinicians call the 'clinical relationship' is important and this is always evolving. It's one of those intangible things that we recognise as important but find hard to describe. It is easier to describe when it's bad.

Understanding issues of power is crucial. Other consumers will best be able to tell you whether a clinician actually understands the role of power issues in 'the clinical

relationship' and his/her practice. See the chapter titled 'Understanding Clinical Relationships' for more on this.

## \* Training your New Psychiatrist

### Training your doctor – Lessons one and two:

- 1) Walk in and sit on his or her chair;
- 2) Turn the clock around so it is facing you.

*2013 MadQuarry Dictionary entry*

So you just got a new shrink! Now, just as puppies without training can become dangerous, as time goes on so can your 'trick cyclist'. A little hard work now can pay off big time in the end and hopefully avoid them coming back to bite you.

Here are some ideas that may help break him or her in:

1. **You are their employer.** On first meeting, remember that you are interviewing them for suitability. They need to decide if they want the job but you are the one with the most to lose if it is a bad fit. Plus, you're paying the bill. They may not be perfect to start with, but do they say things that give you hope or despair? Do you feel like a person or a diagnosis? Only give them as much information as you are comfortable in giving them at first. If they are not a good fit, go back to your GP or clinic and ask them to help find you someone else.
2. **This is temporary.** Should you both decide to go ahead, remember that you are not bound together for life, you are still finding out about one another; either of you can decide to pull out at any time. It's a bit like dating, just hopefully without the awkward stuff about how to end the time together. And at least everyone knows who pays!
3. **Check for trust.** If, after a period of time you still do not trust them with information you know could be helpful, try to work out why not. If this issue is at your end, perhaps ask them for help in sorting it out. If it's at their end, they may not be a good fit for you.
4. **They don't know everything.** Remember that while they may know a lot more about some stuff than you do, there is lots of stuff that you know better than them – including, of course, you! For them to help you they need to know you and what you want and need from them. If you know that you are allergic to some drugs or can identify some of your early warning signs or have tales of other shrink relationships gone wrong, tell them – you don't want to have to go through it all again.
5. **Be honest.** If stuff doesn't feel right, tell them. They are psychiatrists, not psychics! They are not infallible. It is always worth asking if they will change something you don't like rather than just putting up with it, or quitting. There may well be good reasons for what they are doing but you have every right to explanations that make sense to you and the right to state your objections.
6. **Assert your knowledge and preferences.** Let them know, perhaps by Advance Directive, what you want them to do in some common situations. If they need to contact you to perhaps change an appointment, can they leave a full explanation on your answering machine or just a "please call back" message? Can they call themselves "Dr So-and-So" if leaving a message with work or your housemates, or would you prefer they drop the title? Can you discuss what will be written on medical certificates if they are ever needed? Is there someone they can call for you if they are worried about you; if so, what should they say? Under what circumstances do they have your permission to call?
7. **Get to know their preferences.** Find out what services they are willing to offer. Will they read a letter or email in between sessions? How often do they check their phone messages? Will they call you back or wait until your next session? Will they post a prescription if you can't get to an appointment? Do they charge a fee for cancellations? What will they do if they suspect a crisis is happening? If you have trouble talking face to face can you bring a letter with you for them to read and discuss with you in appointment time? Knowing all of this in advance can reduce a lot of stress for you later.
8. **It is your time.** Use this time the way you want it used. You can set the priorities – work out what you hope to achieve and ask them to help you get there. Be wary of them setting goals that don't feel right for you; they know books and what helps other people, but that may not work for you. That said, if we had all the answers we wouldn't be seeing a shrink so do give them the respect that you ask for, and offer them an explanation they can understand for anything you disagree with.
9. **When they get stuff right, tell them.** Just like a puppy, psychiatrists tend to respond better to praise than punishment. In our experience, most are not fond of dog biscuits but who doesn't like a Tim Tam?
10. **It is your decision.** If you decide to end your relationship with your psychiatrist for any reason, let them know why. It may help the next person seeing them but they may also have ideas of who may suit you better. If you are getting drugs from them, remember that going cold turkey is rarely a good idea. Sudden withdrawal from many psychiatric drugs can cause more problems than you had to begin with.

## \* Money Matters

### CPA: Consultant Psychiatrists: Amen

2013 MadQuarry Dictionary entry

Money has a big bearing on the sorts of services we are able to access.

In psychiatry the 'pay for service' principle is corrupted somewhat by services some of us are forced to receive and the fact that Medicare payments to private clinicians, as splendid as they are, have created a very strange category of clinical provider – 'publicly funded private medical clinicians' (thus called because they are largely paid through the public purse).



I NEED THE FOLLOWING SERVICES PROVIDED BY MEDICARE PLEASE:

- \$2000 WORTH OF ASYLUM,
- ONE RESPECTFUL PSYCHIATRIST,
- PEOPLE TO SPEAK WITH WHO HAVE BEEN THROUGH ALL THIS STUFF, AND
- SOMEONE TO TALK TO WHO IS INTERESTED IN RECOVERY.

Private health insurance is not the answer for most of us. For a start, few of us can afford the premiums, even if they would cover us for 'mental illness'. In any case, the reality is that many of the cheaper plans (such as those aimed at young singles) do not include psychiatry. Read the fine print carefully.

Having said that, privately insured consumers who are in hospital may have gap fees fully reimbursed, or even paid upfront by their insurers.

More money matters are discussed below.

### The consumer context

Mental health consumers span the socio-economic spectrum.

Whilst many consumers operate very 'normal' lives, tell few people about their status, and earn high incomes (and thus are able to pay for expensive medical or psychological interventions) many of us fall through the cracks.

Being a consumer not only dramatically affects income for many of us, but it is also costly. Medications are expensive, time off work is common, visits to clinicians are often very frequent.

The inability of the public system to cater to our needs is palpable and as consumers living in society we are as culpable as everyone else for the underfunding of services for all, including people who are homeless, isolated, drug users, prisoners, asylum seekers and the many with histories of trauma and abuse.

See the Our Consumer Place December 2012 newsletter item by Merinda Epstein, 'Plunging out of your social class,' for a discussion of social class and 'mental illness' (available at [www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au)). Those of us who started with less are even further disadvantaged.

### Psychiatrists' fees

Unlike public services, which have state funding, private psychiatrists are paid largely through Medicare, which comes from the Commonwealth.

Fees charged by private psychiatrists vary enormously. There are no recommended fees set by the Royal Australian and New Zealand College of Psychiatry (RANZCP) – the peak body for psychiatrists in Australia. Medicare and the Australian Medical Association (AMA) provide a fee schedule but as a guideline only.

Medicare provides a rebate on many psychiatric services, such as standard consultations. This rebate is based on what is called the 'Scheduled Fee', which is determined by the Federal Government. If the fee our doctor charges us is greater than the Scheduled Fee, we will have to pay the difference (this is called the 'gap' payment).

Note that fees for medical reports, missed appointments and other items are not usually covered under Medicare so we often have to pay the full cost for these.

It's also very important to note that a referral from a GP to a psychiatrist is

necessary to claim Medicare rebates – you can't just roll up. These referrals most commonly cover a short period of time. For longer-term treatment, common in psychiatry, we need a special referral if we want to avoid having to keep going back to the GP and paying just to pick up a piece of paper.

Private psychiatrists tend to have practices clustered around the more affluent suburbs of Melbourne. They usually charge high fees. General practitioners in less affluent areas tend to appreciate the financial constraints on many of us so speak to your GP about the fact that money is an issue when referral is being discussed.

Sometimes psychiatrists have a sliding scale of fees which means that those with the greatest capacity to pay will pay more and people on pensions are 'bulk billed' – this means that we are only charged the fee that Medicare will pay in full, with Medicare charged directly, so that the patient does not have to do anything but sign a form in the doctor's rooms. In between, there may be incremental charges on a sliding scale. We even know of one regional psychiatrist who reduces the fees by the cost of the petrol needed to attend the session.

Psychiatrists also have different policies around how payments are made. Some insist on payment being made on the day. You may need to pay both the Medicare-refundable fee (which you will need to claim back later), and the gap (if any). Others will require you to pay only the gap, which could be as little as \$10-\$15 for a 50-minute session.

### **Payment as part of 'therapy'**

Many of us have heard psychiatrists arguing that we should be paying them more because it's part of taking responsibility for our own mental health. The arguments they often give are:

- Medicare distorts the patient-doctor financial arrangements and too many Australians demand services they don't need because they can get them without any outlay of their own money;
- People can become 'addicted' to the support a psychiatrist gives them and without a monetary incentive may stay dependent.

We question whether it is the monetary incentive that we need in order to disentangle ourselves from some professional relationships. There are many things that clinicians themselves do that make it hard for some of us to move on. The reality is that psychiatrists are dependent on us as well – at least, they are dependent on our money. This is rarely mentioned.

### **Avoiding getting stung**

Long appointments and frequent visits are common in psychiatry. Added to other medical costs, some of which are directly related to the physical impost of 'mental illness' on our lives, it can mean a lot of money.

Ask the psychiatrist during your first visit about his or her fee structure. Try to arm yourself with knowledge about Medicare safety nets before you go so you can ask

informed questions before you commit to a relationship that you can't afford.

Try not to be embarrassed about discussing your financial limitations. Most of us have them. Anyway, you can learn a lot about the psychiatrist's attitudes to many things by engaging with them about money matters.

### **Who pays the bill?**

One interesting issue raised by many young consumers is the negative effect on their mental health of clinicians allowing parents to pay for the therapy their adult children cannot afford. It's a matter of ethics. If the issues being explored are intrinsically to do with family then accepting charity from those implicated in the problem makes things worse for many.

It is always OK to speak to clinicians about your capacity to pay. Talk to the therapist, or ask your GP if he/she can refer you to a bulk billing psychiatrist who is interested in psychotherapy, or some other more affordable option.

### **Allied health services**

Medicare rebates are now available for some mental health services through the Federal Government's Better Access initiative.

If we are eligible we can receive up to 12 individual allied mental health services per calendar year.

Specified Medicare-funded services are available only for patients with a 'mental disorder' who have been referred by a GP or psychiatrist, and who have a Mental Health Care Plan.

Allied mental health services that can be provided under this initiative include psychological therapy services provided by eligible clinical psychologists, and focussed psychological strategies provided by eligible psychologists, social workers and occupational therapists.

If you are not sure if a particular practitioner or service is eligible for a Medicare rebate, make sure you ask. The service provider will know the answer immediately.

You can find out more information about Medicare rebates for mental health services, including a list of eligible 'disorders', at <http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-ba>.

All of this aside, most clinical psychologists and counsellors in private practice are fully fee-for-service and thus out of reach for many of us.

There's a systemic aberration which means more than 80% of practicing psychologists work in wealthier suburbs of large cities where there is a sufficient number of people prepared to pay for their services. This means they are placed with little relationship to the distribution of need.

Of course, there are some clinicians who work in poor, regional or country areas, and some who have a sliding fee scale. The problem with them, however, is always their waiting lists.



## Medicare Safety Net

It's not easy to understand how the Medicare rebate and threshold system works.

Unfortunately, due to the sometimes frequent and often ongoing nature of some conditions associated with 'mental illness', not to mention the high fees charged by most private clinicians, consumers have a particular need to get their brains around these issues.

The basic concept is that poor people and people with chronic illness – that is, illness that goes on for a long time like some 'mental illnesses' – are protected by the structures of Medicare.

The second idea to note is that unless we are bulk billed (where payments from Medicare are managed automatically and are exactly equal what is charged by the clinician), we will have to pay money to doctors, with the amount we pay growing bigger and bigger the more often we see a doctor, or the more they charge.

The Federal Government's social justice policy suggests there should be cut off points within Medicare; a point at which "enough is enough" – these are called thresholds. When we reach a specific threshold (where we have paid out money up to a particular specified amount in a calendar year), the refunds provided by Medicare increase. Of course, we have to provide proof of this through production of receipts showing the fee for service we have paid or the 'gap' (anything we have paid beyond what Medicare will refund).

There are two of these trigger point thresholds – one for singles and one for families – and the threshold levels are significantly lower for people receiving Centrelink payments than for those who are not.

There is also a further complication of an Extended Safety Net Threshold, which is designed to alleviate the financial pressure on those with very high medical needs. This threshold jumps into gear at a lower level for pensioners than it does for all other Australians regardless of health status, prognosis or any other determining factor.

Medicare keeps careful records (including online records, which you can access over the internet) of what has been paid by you and what has been refunded. Medicare will contact you when you have reached either the first or the second threshold.

### Keeping track

All of this can be extremely complex but it is vital that as consumers we understand how it all works. Too many people with a diagnosis of 'mental illness' are not receiving the refunds they deserve because they are confused about how it works or don't ask for the right records.

The easiest way to start keeping track of it all is to get a shoe box and be strict with yourself about collecting and putting in the box all receipts for all money you have paid out for all doctors.

The Medicare Safety Net scheme runs from January 1 to December 31. Around

every three months during this period (or more regularly, or less regularly – but make sure you do it) take a trip to your closest Medicare office and take all your receipts with you. The officer there will be able to sort out what is refundable and what is not. Then clear the box and start again.

Refunds will be paid into a designated account (Medicare became cash free at the end of 2012).

All is not lost if you have mislaid receipts. Medicare will be able to give you a reading telling you which ones are missing and your doctor will be able to reissue them.

Information on the Medicare system is available at <http://www.humanservices.gov.au/customer/services/medicare/medicare>

### Tax

You may be able to offset some of your medical expenses that have not been refunded against your income when you lodge your annual tax return – check with an accountant, a financial counselling service, or call the Australian Tax Office for clarification.

## The Pharmaceutical Benefits Scheme & Safety Net

The Pharmaceutical Benefits Scheme (PBS) is an Australian-wide scheme that is designed to make medicines more accessible to all.

Apart from subsidising medicines, the scheme has responsibility for the PBS Safety Net, which is designed to kick in once an individual or family has reached a certain level (or threshold) of medication outlays in any calendar year.

After the safety net has been reached, most medications are free.

There are three different safety nets:

- The General Safety Net Threshold;
- The Concessional Safety Net; and
- The Repatriation Pharmaceutical Benefits Scheme (RPBS), which covers war veterans and their families.

The safety net tally starts on January 1 each year and runs to December 31.

Each year the three different safety nets increase incrementally in accordance with the Consumer Price Index (CPI).

You can find the latest safety net levels at <http://www.medicareaustralia.gov.au/provider/pbs/pharmacists/safety-net.jsp#N10009> or call 1800 020 613 and ask to be sent a brochure.

Once you have reached your safety net threshold, your pharmacist can issue you with a safety net card. In order to do this the pharmacist will need to see your Medicare card, your prescription record form and your concession card (if appropriate).

On your PBS card you can include your spouse or de facto, family members under the age of 16 and dependent full-time students under the age of 25.

### Keeping records

Records are important if you want to make the most of the PBS Safety Net.

Some pharmacies keep good records for you – this is a big incentive to always use the same pharmacy.

Pharmacies may also provide you with a card which you can take with you so that if you get scripts made up at another pharmacy the information is transferable to your own pharmacy. Note, though, that you don't have to have this card to get a script filled; just ask the pharmacist to record what they have prescribed to take back to your pharmacy.

It is advisable to also keep your own records. Things can go astray even with the best of systems in place. This will ensure you know as soon as you have reached the safety net threshold.

### What to ask your doctor

Even with the PBS in place, medications can be expensive. Try to gather as much information as you can about what medications you're being prescribed. Ask your doctor:

- Is s/he prescribing anything that is not on the Pharmaceutical Benefits Scheme? (If they're not listed on the PBS, you will have to pay full price.) If so, what are the benefits of this particular medical drug? Is it so important that its worth taking out a second mortgage on your house to pay for it?
- Could generic drugs be used that would mean your initial outlay would be less? Generic drugs are like home brand products in the supermarket. They cost less than the brand name but are pretty much the same.

### What to ask your pharmacist

Your pharmacist can be a good ally in ensuring you're getting access to all your entitlements. Ask them:

- Can they give you information about the PBS threshold and help you to understand it better?
- Can they keep records for you? Are they happy for you to check in from time to time to see how close you are to the threshold?
- Can they give you a card so that if you do get medicine somewhere else your records will remain intact?

### Other things to note:

- **Hospital-dispensed medications:** If you are admitted to hospital, check that the medications you are given will be added to your count for the safety net threshold. They frequently don't think of this and may need reminding.
- **20-Day Rule:** If you buy a PBS medication within 20 days of the previous script being filled for that same medication, the cost may not count towards your PBS threshold. If you have already reached your threshold you may still have to pay for this second script.
- **Authority Script:** Some medications are only available on PBS for certain 'illnesses'. This requires your psychiatrist or GP to ring the PBS and obtain 'authority to prescribe' before they give you the script. Some medical drugs can only be authorised by specialists.

To find out more specific information about the PBS, go to [www.health.gov.au/pbs](http://www.health.gov.au/pbs) or call 1800 020 613.

To read more about the PBS safety net go to <http://www.medicareaustralia.gov.au/provider/pbs/pharmacists/safety-net.jsp>

### Some consumer criticisms of the PBS Safety Net

For many consumers, social and emotional resources are scarce. We may find relationships difficult and end up losing our community and living on our own. Unfortunately, the PBS Safety Net discriminates in favour of families, with thresholds being the same regardless of how many people are contributing towards them. This is not in the interest of many people with 'mental illness'.

Accurate record-keeping is also often quite difficult for some consumers, which can mean we struggle to keep track of where we are up to in reaching our safety net.

Another criticism of the PBS Safety Net is that no means test is applied. As mentioned elsewhere, many consumers work fewer hours, earn less money per hour and have chequered careers interrupted by episodes of 'illness' and recovery. Even if we are not on a disability support pension, we often earn less than the average wage – sometimes much less. Many of us can only cope with part-time work.

Medicines are extremely expensive and the jump from \$4.80 per script for people with concession cards to the full price is enormous. This is a strong disincentive for us to try and get off the disability pension.

### Clinicians as small business operators

Our community sometimes forgets that doctors, psychologists and counsellors working in private practices are running small businesses. We may be surprised and sometimes even angered by the charging of extra fees or the refusal to undertake extra tasks that come outside those things that are covered under Medicare.

Clinicians must take some responsibility for the angst this can generate. While in some circumstances they seem to want to sit above the grubbiness of the

marketplace, adhering to lofty ideals and principles of serving the sick and the dying, it's clear that most are also clearly interested in making money. In fact, many specialists make huge amounts of money. The community is not blind to this. It can therefore be very aggravating when a seemingly paltry request is refused or charged for.

GPs and other primary care providers such as clinical psychologists sometimes charge for the phone calls, the letters, and the meetings that enable the communication we want and need to take place. They might have a policy that all patients have to come into their rooms (and pay a consultation fee) when they pass on information to another clinician.

Within reason, such charges do in fact make sense – such clinicians are in fact running small businesses.

Of course, there are also cases of great generosity among clinicians. GP practices in very poor areas often bulk bill everyone and few hesitate to communicate with whichever specialist we need for free. Other practices may charge for consultations but not charge excess for letters or other forms of communication. Most will bulk bill all pensioners.

There is absolutely nothing wrong with calmly asking the practice manager or your doctor for a list of fees for all items charged, as well as consultation. That way you will start off with your eyes wide open and won't get nasty surprises along the way.

## \* Understanding Clinical Relationships

**Useful therapists: noun** Whenever I want to say something to my partner and I haven't got the guts, I say, "My psychiatrist says ...". It seems to work. Whenever my partner wants to say something to me and he hasn't got the guts he says, "Billy (the dog) says..." That seems to work too. The only conclusion we can sensibly draw is that my psychiatrist must be a dog.

*2013 MadQuarry Dictionary entry*

Many of us develop useful, even life saving, therapeutic alliances. Nonetheless, the relationships we develop with mental health clinicians are unusual and artificial in many ways.

Here we outline 10 issues that can be relevant to relationships, and offer some thoughts about how we can consciously shape these formal exchanges (as much as we can).

## 1. Dependence

Many people understandably fear becoming dependent. Often to some extent we are, and this is not necessarily entirely a bad thing, or entirely our fault. Many of the clinicians we see are also dependent on us – some are certainly dependent on our money.

Some of us are so determined not to become dependent that we completely shut off from developing meaningful relationships. This is understandable, as the risks are relatively one-sided. However this can hinder opportunities for personal growth.

## 2. Boundaries

Boundaries are an important concept for professionals, although sometimes overstressed.

Mental health professionals tend to believe that 'professionalism' demands that they create and maintain boundaries, and that this protects their clients.

However, consumers who have had multiple clinicians know that boundaries are drawn idiosyncratically. We can experiment by pushing boundaries to better understand them.

Also, different consumers have different ideas about boundaries (and these can change over time). For example, glimpses into a therapist's private life can be very helpful, frightening or annoying.

Some of us like to maintain distance, or even try to make ourselves less likeable to avoid developing overly 'touchy-feely' relationships.

On the other hand, some of us strongly prefer that these boundaries are looser – if boundaries are too tight and rule-driven we might feel controlled, undignified and unhappy. Our own boundaries need to be self-defined.

At their extreme, therapeutic arrangements are governed by a 'Contract of Therapy' (particularly associated with some forms of psychotherapy) which gives us little or no room to move once it is signed.

Depending on our communication preferences these documents can either reassure us or scare the living daylights out of us. Once signed, it is part of the therapy. It won't go away. Decide early whether you're going to leave.

## 3. Boundaries as excuses

Like confidentiality, boundaries can be used as an excuse for poor communication.

Flexibility is essential, allowing sensitive professionals to explore boundary issues with consumers in an open, safe and transparent environment, free from any games.

## 4. Malpractice

Sometimes boundaries are shattered by the party which has the most power in the relationship – in this context, the mental health professional.

It's important to know that if we are touched inappropriately, sexual advances are made, or sexual images are used unsuitably, for example, we should be concerned, no matter how 'nice' and 'caring' the person might seem.

We need to be clear that none of this is our right and none of it is our fault. If we are uncomfortable with anything to do with personal boundaries we must try and find support to confront these issues and remove ourselves from the relationship. This is a big decision to make and some people do not follow through with a complaint. Unsupported it will be extremely hard.

See the sections titled 'Dealing with Inappropriate Behaviour by Clinicians' and 'Making a Complaint' for information about places you can go to for help or to make a complaint.

## 5. Political views and moral imperatives

Some people believe that anti-psychiatry is a moral imperative for consumers whilst others perhaps once thought this way and have moved on to a more accepting stance. Others still are perfectly comfortable with psychiatry, and happy about campaigns that promote compliance within a medical agenda.

People hold a wide range of views. It is not weak-willed to seek out help from psychiatry/psychology or counselling. Nor should it be seen as wrong to seek and promote information from the consumer/survivor movement. We need to be encouraged to talk to others who have travelled the same paths and enabled to think well of the choices we make.

## 6. Ethics and professionalism

There is often a difference between the patient/client code of ethics and the professional code to which clinicians ascribe. Sometimes these differences compromise practice and communication.

Issues around confidentiality, duty of care, being competent and in control, and detailed record-keeping are part of the fabric of clinical ethics and professionalism. For us, however, ethics might include the requirement for clinicians to listen to us respectfully at all times, adhere to our advance directives, practice in a way that enables the dignity of risk, challenge the social structures that protect perpetrators of abuse and trauma, and make a stand on behalf of their clients/patients around the social issues that often have determined our lives.

## 7. Intelligence

Often people say that they can't bear being 'in therapy' with clinicians who are not as intelligent as they are. When they find it easy to 'read' the clinician, second-guess their next move and manipulate the therapy, they are not satisfied and become pessimistic about anything changing in their lives.

In the public sector this can be diabolical because there is almost no opportunity for changing your primary worker.

## 8. Inexperienced practitioners

Most people practicing psychotherapy attend regular supervision from more experienced practitioners. This is like having a mentor and has proven to be imperative for the survival of many young practitioners in a harsh environment.

Sometimes, however, it can be like learning the 'sins of the father'. All apprenticeship models hold risks of some young clinicians copying bad practice.

## 9. Referring friends

Take care. Some of us have done this and it has gone pear shaped.

It's imperative to remember that we all appreciate different approaches to clinical practice: different theoretical underpinnings, different ideas about medication, and so on.

If you have found a therapist/clinician who is useful, write down what they do which works for you. Think it through carefully on several axes of importance. For example: 'politeness, non-patronising and good bedside manner' or 'knowledge of the most up-to-date psychotropic medication' ... then, instead of recommending her/him per se, say, "This is what my therapist's practice includes ..." or, "This is what I appreciate in my clinician's behaviour/practice ..." then people can make up their own minds.

## 10. Ending a therapeutic relationship

Concluding long-standing relationships with a therapist is difficult. After all, we have invested a large part of our lives in this transient, strange relationship which is disconnected from the fabric of the rest of our lives.

See the section titled 'Walking Away from Clinical Relationships – Dignity Intact' for more on this topic.

## \* Communication with Clinicians

**Confidentiality: noun** The clinician's office is not a confessional! If you want something kept confidential the best form of attack is defence! Don't say it.

*2013 MadQuarry Dictionary entry*

Communicating with mental health professionals can be challenging. Here are 10 common challenges and some thoughts about making the situation work better for you.

## 1. Communication is bound to feel weird sometimes

Of course there may be communication difficulties – you are (probably) in their space, they are probing your mind, and they may have the power to lock you up involuntarily.

Many of us don't want to offend or "provoke" professionals, and negative emotions (including a "lack of gratitude" on our part) are too often pathologised.

Sometimes it is hard to get heard because what we have to say is too complex and/or too deep or we experience it as a feeling rather than a thought. Sometimes we self-censor because what we were just about to say seems too presumptuous, too stupid or too unimportant.

Many of us who have experienced childhood abuse and trauma can find it extremely difficult to talk about it and often we come out very slowly over a considerable amount of time. Honest, comfortable communication can be difficult under such circumstances.

Don't take all the responsibility for communication that feels weird. When you're not used to it, sitting in a space that belongs to another person who you do not know and who has the power to interpret your mind can be a challenging experience.

## 2. The communication is uneven and non-reciprocal

Few of us want to be always the takers and never the givers. Firstly, giving is a delight for many and secondly, giving is empowering.

But when we know the relationship has special rules (that we often aren't entirely clear about), we can be afraid to demonstrate everyday reciprocal kindness.

For some of us it's a good idea to be up front and simply ask for an explanation of the clinician's boundary rules. Perhaps this is at the cost of a little adult dignity but for some it is worth it.

## 3. "They know more"

It's easy to believe that a clinician's many years of training means that they know more than you do. However, the training of both psychiatrists and psychologists tends to lack input from those of us with personal experience. Also, their education tends to be elitist, hyper-competitive and narrow (excluding social context insights from sociology, history, politics and anthropology).

This doesn't mean that they have nothing to say, but they don't know everything!

## 4. "What should I call you?" Dealing with titles and names

This is a big issue for some and a non-issue for others. You can either avoid using anything until you figure out what to do, or you can just ask what title/name is preferred.

If you are uncomfortable with addressing someone as 'professor', for example, you can choose to make a game of it (if the relationship is worth it) and call her 'professor' to her face and use some good old nutcase humour behind her back.

## 5. Not understanding the terminology

For many of us, being with a clinician is a bit like being in a foreign country. This means that first we have to work out what people are talking about and then we have to decide whether it really does apply to us.

The language – 'psych. speak' or 'psychobabble', as some of us call it – can be seen as a sort of special mental health dialect that few people outside those narrow professional fields can speak. For example, what do we say when we are confronted by someone asking whether we're 'hearing voices'? What does this mean? If we don't have a base line – not much. If we get it wrong it can have huge consequences.

In a hospital situation, other patients are usually the best interpreters.

## 6. Projection, transference & counter-transference

Some therapists/clinicians will talk about psychological 'projection', which describes a defence mechanism in which 'we' and 'they' unconsciously give to each other the attributes in ourselves that we don't like.

However, our observations are that often the therapist/clinician is more likely to interpret projection from 'patients'/'clients' but far less likely to locate it in themselves. They are also unlikely to call it when they see it, leaving us totally in the dark.

'Transference' is another term clinicians use. Transference is characterised by unconscious redirection of feelings of one person to another. For instance, you might instinctively mistrust somebody who resembles an ex-spouse in manners, voice or external appearance; or you might be overly compliant to someone who resembles a much-loved childhood friend.

Like projection, we need to know about this concept because it is one of the understandings that drive some clinical practice.

'Counter-transference', meanwhile, as its name suggests, is where the therapist/clinician begins to transfer her or his own unconscious feelings to the 'patient'/'client'. For many of us this comes across as hardly surprising. The difference is that it is the responsibility of the therapist/clinician to be constantly aware of counter-transference because they are the paid professionals. We do not have this responsibility.

## 7. Power differential

No matter how 'nice' our therapist/clinician/counsellor is, the relationship involves unequal power. This is because of the unequal status of the social role of 'clinician' and the social role of a 'patient' or 'client'.

To some extent, at least, each player knows it is a game. But games create poor communication.



Keeping notes as our counsellor/clinician is talking, bringing in notes to guide us, showing we have read about our diagnosis, and asking about our medication without just accepting it are ways that some of us have tried (mostly unsuccessfully) to even up these relationships.

Other strategies include asking the clinician about his/her theoretical assumptions and approaches and even asking to swap seats with the clinician (literally – she sits in your chair; you sit in hers; it can feel weird but it does send a message that the clinician's authority should not be taken for granted).

However, be warned: some (hopefully a minority) of clinicians will perceive our assertiveness as unhealthy. Don't worry. It's probably got more to do with their loss of power or lack of experience than with anything we might or might not have said or done.

## 8. 'Pathologising' everything

Doctors and psychologists are trained to look through the binoculars of individual pathology. Therefore they are searching for signs of psycho-pathology as they listen and watch us. In a hospital setting, nurses and allied health professionals also get caught up in this way of seeing the world.

The unfortunate result of this is that communication between us all becomes wary as we try and second guess what we need to do and say in order to achieve what we need. Some of us fall silent for fear of what might be construed by what we say, but then we find words like 'passive aggressive' or 'personality disorder traits' may start appearing on our files.

Many people with a mental illness diagnosis describe how they learned to be a 'good patient' because being 'good' led to being treated better by the mental health system. However, these 'good' behaviours – trying to be silent, for example, or saying what you think the clinician wants to hear – are not necessarily in our best interests.

Judi Chamberlin famously wrote in *Confessions from a non-compliant patient* (2011): "I've been a good patient, and I've been a bad patient, and believe me, being a good patient helps to get you out of the hospital, but being a bad patient helps to get you back to real life."

## 9. Confidentiality

Confidentiality is important. Because of community prejudice it's important that we remain, as far as possible, in control of who knows what.

This is not as straightforward as it might appear because when services claim your information is confidential they often forget to tell you about the one major exception – everyone on this rather nebulous entity called, 'The Team' is privy to **everything you say**. Mostly we don't even get to know who is on this 'team'. Sometimes the definition of 'The Team' stretches to include nearly everyone who works in the medical field. Be careful when you divulge very personal information.

On the other side of the coin, clinicians sometimes use confidentiality as an excuse for poor communication with others (even if we have asked them formally in an Advance Directive to communicate with them about us). This is a special problem when we are in same-sex relationships or it is our friends (and not our family) who support us. Even if it feels weird, it's sometimes useful to use the term, 'primary carer' to describe these relationships because this is a term systems-focussed clinicians more readily respond to.

More about confidentiality issues is provided in the section titled Privacy, Secrecy and Confidentiality.

## 10. Superiority

Many clinicians are quick to tell you that they had to do many years of training before they qualified for their profession. This is true. But that doesn't mean their knowledge and experiences, particularly as they relate to us, are superior to ours.

Sometimes psychiatrists are critical of the training of psychologists because so much of it is "rats and stats" and psychologists are critical of the training of psychiatrists because, "it lacks theoretical underpinnings".

From our point of view, the essential points are rarely put forward by either group. They include:

- That there is almost no input from those of us who have personal experience of 'mental illness' into their training. How can they possibly know even the basics without this? There is resistance to our approaches. There is little faith that the consumer body of knowledge is knowledge at all or that we have anything to teach them. Interestingly, there are more consumers with Masters and PhDs in education than there are other clinical educators with even a rudimentary diploma qualification.
- That both groups are intrinsically elite. Graduates are generally drawn from privileged class backgrounds and see their destinies in professions that make a lot of money and 'rightly' have a lot of power over their 'patients'/'clients' and in society.
- That undergraduate courses are unhealthily competitive and non co-operative.
- That there is little or no input from the important fields of sociology, history, politics and anthropology, which look at clients/patients not as individuals, not even just as people, but also as major players within a social context in which psychiatric services and relationships are always played out.

## \* Advance Directives

**Advance Agreements:** We wanted 'directives' and we got 'agreements'. We wanted legal standing for everyone and we got it for a tiny proportion of people who are held under the new Mental Health Act (as important as they are). Isn't that what politicians do? They promise a lot, consult with too many people for too little time asking the wrong questions and then justify giving us a pittance.

*MadQuarry Dictionary entry 2013*

An 'Advance Directive' is a document that enables someone with a diagnosis of mental illness to keep control of their lives when turmoil sets in for whatever reason.

An Advance Directive can be either a legal document (as in Scotland, for example), or an informal document. At the present time there is no state or territory in Australia that has legally binding Advance Directive legislation. Despite this, some people still choose to make informal Advance Directives. Sometimes they say that both the process of putting together such a document and sharing it with treating professionals is as important as the end result.

In the new Victorian Mental Health Act, due to enter into law in 2013, clinicians in public services working with people being held under the Act will be required to take into account the 'Advance Statements' of patients. This is a step forward, though there are flaws in the drafting of this legislation from a consumer perspective. 'Advance Statements' are weaker than 'Advance Directives'. Consumers are lobbying for the introduction of Equal Opportunities legislation which will make Advance Directives legally binding for all people with mental illness.

Some clinicians see Advance Directives as 'Ulysses Agreements'. This is derived from the myth of Ulysses who, so scared of being attracted to the evil sirens on the banks of the river, got his men to tie him to the mast of his ship to stop him doing something foolish and perhaps deadly. Clinicians who use this analogy are usually thinking of people agreeing to forced treatment in advance (conceptualised as 'when they are well') to ensure they don't do anything to harm themselves or their reputation when they are 'sick'.

Other clinicians, and some people diagnosed with mental illness, conceive of Advance Directives as a therapeutic tool. Neither Ulysses Agreements nor 'Advance Directives as Therapy' are used regularly in Australia.

Advance Directives are NOT treatment plans, though they can be about treatment, outlining in advance what works for us and what does not – what we are allergic to, which treatments do more harm than good, what is likely to make us dissociate, who we do and do not want to visit us, etc.

Advance Directives are written, owned and controlled by the person diagnosed with the mental illness. Clinicians, spouses, lovers, family, friends and possibly co-workers may be asked to read and sign off on the document.

Treatment plans, on the other hand, are, in practice, conceived and written by clinicians and signed off by the person with the diagnosis of mental illness – often to keep the peace.

## Hints for writing an Advance Directive

For instructional advance directives (i.e. those related to treatment) to be useful they have to be:

1. **Practical:** something that clinicians will read and can do something about;
2. **Specific:** i.e. they should name the medication, state the exact problem and your response to it (show you have clearly thought through this document);
3. **Contextually sensible:** don't hand a huge document to emergency department staff because they won't read it – perhaps an authoritative letter from your psychiatrist might work better in this situation;
4. **Not too angry and demanding:** it will be resented and no one will refer to it other than to perhaps give you another diagnosis;
5. **Instructive:** if you can think of the easiest ways your needs can be met, suggest these and make it clear that you're trying to help not hinder;
6. **Clear and concise:** Look at it through the eyes of the reading clinician where possible. What do they want to know?
7. **Kept up to date:** An out-of-date Advance Directive not only can bring you trouble, it also increases the cynicism amongst treating staff about the worth of these documents. Work out where up-to-date copies are to be kept, who can distribute them and to whom.
8. **Signed off** by as many people as possible with whom you want to be involved;
9. **Signed off** by a psychiatrist to say you are of 'sound mind' when you put it together (this is helpful but not always possible);
10. **Distributed to everyone who is included** in the document: psychiatrist, GP, pharmacist, primary carer, special friends, family, counsellor, clinical psychologist, boss (if it's a Workplace Advance Directive), work colleagues.

## Narrative or legal

Different people will prefer different approaches to documentation. As there is no enforcement in legislation yet there is no right or wrong way to present an advance directive, but it is sensible to think about the consequences of each approach.

A **narrative style** may be best suited where you, in partnership with your clinician, wish to use the document as a therapeutic tool as well as an instructive one.

However, they can put people off because they can require a lot of reading. This style may also lead you to divulge more personal information than you intended, putting your privacy at risk.

Many people prefer something that looks as authoritative as possible and will therefore opt for a **legal style** advance directive. Organisations such as the community legal centres and friends or relatives who are trained in the law can help advise you how to write something in this manner.

However, there are things to be considered here too. Firstly, it is easy to forget that these documents are only *quasi-legal* documents. They have NO legal authority. It's important not to have expectations that can't be realised.

Secondly, there can be animosity between some lawyers and some psychiatrists over these documents, both because these professions are naturally competitive (dare we suggest), but more importantly because they sometimes have very different charters in relation to mental health issues. It is possible that some psychiatrists might see lawyers as manipulating your ideas if your document looks like it has been drafted by a lawyer.

### **Content**

We sometimes talk of a 'four-in-one Advance Directive'. This just means there are, in effect, four Advance Directives which can (but certainly don't have to) be used together or separately:

1. The first might include our own early warning signs of trouble ahead, and what we want ourselves to remember to do. Hint: this is the personal part of the advance directive and you may choose not to show it to anyone. Also, experience has taught some of us not to put it first because clinicians are more comfortable telling us what we should do rather reading what we would like them to do. Conceptually it is first; for practical reasons, you may want to put it last.
2. Instructions for psychiatrists and clinical psychologists about what you would like them to do if things go pear-shaped. This section should also include information for clinicians in services, as well as emergency clinicians.
3. Instructions for what you need from your friends and family.
4. Instructions for your work, detailing what they need to do (and not do) if things get out of hand or you need help.

These can be mixed and matched. We do not have to give all four Advance Directives to anyone and we should try and resist attempts by anyone to turn these documents into tools for therapy alone. If this is done they will lose their integrity as an instructional tool.

## **SECTION 4: Troubleshooting**

## \* Walking Away from Clinical Relationships – Dignity Intact

**Exit Plan: noun** Life's never that predictable.

*2013 MadQuarry Dictionary entry*

We hear so often of people diagnosed with 'mental illness' who either 'lose their services' and are upset by this, or are really scared that they will lose their service if they dare to show any improvement in their mental health.

Many of us have experienced this ourselves. We may know that everything is not OK for us (and we suspect the clinicians know this too), yet we are being told we have improved to a point where we can cope on our own. The tendency is for us to either:

- a. Try to prove we're not OK (which means that we in fact end up becoming 'sicker' in order to get well), or
- b. Pretend we are much more OK than we know we are in order to avoid being seen as dependent and needy.

Shame and guilt are often the mainstays of the lives of people diagnosed with 'mental illness' – shame that we have achieved too little in our lives; guilt that we are still dependent on others (sometimes our parents).

The judgmental language of 'high functioning' and 'low functioning' labels are too often used as a tool to regulate client flow through a services.

### THE THERAPEUTIC RELATIONSHIP



It seems ridiculous that mental health services would seek to protect their throughput figures and hence funding in such a way that they augment the burden of shame and guilt for consumers. However this often happens in the terminating of therapeutic relationships.

Of course, sometimes this difficult event is handled well by clinicians. But in too many cases:

- We feel we are treated like imbeciles or children; we feel like we can see right through what's being done in our names but without our permission;
- The service is so desperate to get us out of there (for whatever reason) that the process is corrupted, hurried and ineffective.

### The role of services in creating dependency

When we look at the language of psychiatry we see why we get caught up with services and sometimes find it difficult to 'move on'. Terms like 'co-operative' and 'compliant', are juxtaposed continually against terms like 'non-compliant', 'difficult' and 'manipulative'.

To be a 'good patient' in the eyes of the system, we often have to acquiesce to the expectations of the system and those who serve it. It's good to do as you're told, look after the clinicians and second-guess what they want you to do and say.

However, when 'they' decide it is time for you to 'move on', all of these 'behaviours' that were considered attributes get inverted – they become signals of dependence.

This is very hard to understand for many and it is made harder because we are so used to taking on the guilt load. Many of us just assume we have done something wrong.

### When there's no choice

Choice to terminate a particular relationship is much more difficult if we have no say in whether we are locked up or 'treated' at all, as is the case with people who are being 'treated' under the Mental Health Act.

Choice is also impacted by scarcity – choice is very uncommon for people receiving 'treatment' by Public Mental Health Services and Community Health Services, for example, because these services are so stretched. Bad luck if you and the therapist don't get on. Bad luck if you have a forbidden diagnosis. Bad luck if you didn't impress the 'Intake Team'.

People in rural and regional areas are another group who have little choice when it comes to selecting and moving on from therapists/clinicians, simply because there are so few alternatives and rarely affordable ones.

### When it's the clinician's choice

Most of the clinical groups that provide therapy, case management or support, particularly over long periods, learn protocols for bringing therapeutic relationships

to an end. They know it is hard – often for both parties – but they are the ones who must shoulder the responsibility.

These protocols are supposed to make the ‘termination’ (great word!) gradual so that we can get used to the idea of not having this support in our lives. This process happens over quite a long period, with frequency of visits being reduced and a lot of discussion about ‘where to next’.

Unfortunately there are two major problems:

1. Public services often can't afford the time for clinicians to participate in this transition process properly;
2. Some clinicians are transparent and badly skilled and we can see straight through their ‘finale performance’. This leaves some of us feeling demeaned and manipulated which indeed we often are.

If you feel undermined it's OK to be cross. Many of us have experienced the same thing. However, don't cling on past the point of dignity. Leave abruptly if this feels like a good way to get your power back, and find other consumers for support, at least in the short term.

### **When it's our choice**

Some of us blast out of public services as soon as we are no longer retained under the Mental Health Act. We realise the damage that has been done by being incarcerated and having so very little control over our lives and bodies.

Many of us hate the medical drugs we have been forced to take, think the Diagnostic and Statistical Manual is a fraud and that medicalising our personalities is unethical, and we have no problems at all steering clear of all medical interventions in the future – if we can. The fact that ‘mental illness’ is the only illness where one can be forced by law to endure unwanted treatment is a great motivation for escape.

Sometimes, particularly in the case of private psychiatrists, psychologists and counsellors, it is left to us to decide when it's time to end the therapeutic relationship. This presents a whole new set of challenges.

Surprisingly perhaps, people with some choice can get almost as trapped as people with no choice.

After what can be years of ‘therapy’ it can be hard for some of us to trust our own judgment, especially if it runs contrary to that of the ‘therapist’ we have learnt to rely on.

This is a particular trap if we are purchasing ‘therapy’ in the private therapy market. It is very easy to forget that psychiatrists, clinical psychologists and counsellors are running businesses.

Some of us may even start to take responsibility for looking after the therapist. We start to believe we must stay. These strange dynamics can capture us.

Power and control issues are inevitable. Some of us work hard at being a ‘good’ patient/client. This can also make initiating leaving hard.

We can also lose power when decisions that we make are pathologised by the other person in the room. It is more difficult to make independent decisions to leave under these circumstances.

Larger social institutions that govern community behaviour also influence us. Gender and cultural issues sometimes render women silent; levels of education, social class and homophobia on the part of the clinician, for example, all affect the decisions we make.

What moves we make in such circumstances will depend on whether we get mad and whether we get silenced.

### **When it's time to move on**

Here are a few things you can do when you know that it's time to finish a therapeutic relationship but you're having trouble moving on.

#### **Reconceptualise your relationship to ‘mental illness’ and therapy**

If we start to see our emotional distress as having a positive side – life-changing ‘break-throughs’ rather than simply negative ‘break-downs’ – we increase our capacity to make informed choices.

We are no longer beholden to the therapist – we are paying for them to provide a service (even if that's through Medicare). It's a business transaction.

Thinking of our therapy sessions this way can give some of us the confidence to speak up.

#### **Seek stories from others**

This is when support and advocacy groups really come into their own.

Seek out and speak to your group and other friends who have terminated therapeutic relationships successfully.

Ask them key questions about what they did and how it went. How long did it take? What was the reaction of the therapist? What did they create in its place? Where else did they look for support? Did they find any websites that helped?

Surprisingly most doctors and psychotherapists know almost nothing about support groups and advocacy groups, even those in close proximity to their practice. This is a product of the limitations of their training.

It is also true that many private clinicians are concerned about support groups on the web. Some of this is well founded and some is not wanting to let go of their power.

#### **Bring a friend along**

If we have an Advance Directive, our clinicians will hopefully be aware that there will be times when we want someone to come with us to an appointment (there might



be a bit more resistance if we spring it on them).

It's important that we bring along the person we want to bring, not the person we think the therapist might want or expect us to bring.

## Ending a harmful therapeutic relationship

Sometimes it is the patient who knows that a relationship must end. Obviously this includes instances (thankfully rare) where there have been gross illegal acts such as rape or assault by clinicians. However, harm is not always so obvious.

Other causes of harmful relationships might include:

- A serious personality clash with uneven power deliberately manifested;
- Major problems caused by misuse of power;
- People's lives and needs being treated with disdain;
- Total lack of trust in the relationship;
- Judging, belittling, undermining, bullish etc. problems with the clinician's behaviour.

See the sections titled 'Dealing with Inappropriate Behaviour by Clinicians' and 'Making a Complaint' for more on this.

## \* Accessing your Files

**Irony: noun** When information about you is now free even though you aren't!

*2013 MadQuarry Dictionary entry*

People differ greatly about how much they want to know about the information that is kept about them and then informs future interactions with individual clinicians and with the system.

Some consumers keep as far away from looking at their records as possible. They don't wish to put themselves through even more pain.

Some can't be bothered – *"Once I'm out of there I'm out and I don't want anything to do with it"* – while others take a moral stand that these records belong to the clinicians and were never meant for our eyes.

Other consumers argue that they already know from the clinicians' behaviour that terrible things have been written about them and they want to prove they are not

just being paranoid. They want proof that the words they expect actually exist (often they do).

Others want to add to the file in order to correct it, and a few are looking towards taking legal action and need information from their file in order to do so.

And consumers on Community Treatment Orders and undergoing involuntary treatment are required under the Mental Health Act to be shown their personal histories before they are due to appear before the Mental Health Review Board.

There is no right and wrong approach. It's up to each person to decide whether or not they want to access information, bearing in mind that there are a lot of things we can't do with it even if we want to.

## Language

The general consensus amongst mental health consumers is that much 'mental illness' fits into a particular category of 'medical problem' that also includes obesity, chronic pain and fibromyalgia – these are all 'conditions' that are seen as 'unworthy' both by clinicians and the general public.

Records that are kept about people who have been diagnosed in any of these ways are especially fraught.

Clinicians selectively choose the information they are going to record, in what form, and using what vocabulary – decisions that are unavoidably influenced by their own particular worldview and society's views about people labelled who receive these diagnoses.

Because many clinicians pride themselves on being 'scientific' and 'dispassionate', most of them are unaware of the social conditioning that plays such a big part in how they think, how they frame conversations and what they keep as records.

There is also a huge variation in recording habits and preferences. This is especially so for psychiatrists and psychologists working in private practice. Some clinicians write so much that there is a tendency for us to stop talking so we can give a rest to our therapist's tiring writing arm. Others write absolutely nothing except perhaps a word or two after we leave the room.

Those clinicians working in public services, in a role of 'case manager' or therapist, have less choice about how much they write and how. There's a largely unspoken formula that is expected, as well as forms designed to standardise these files so that everyone in the service is able to make easy sense of them.

Unfortunately, with standardisation comes the greater reproduction and perpetuation of language that many of us find offensive, wrong, blaming, unsubstantiated, typecast and sometimes cruel.

In hospital settings, many people are privy to everything that is written about us. This is the territory of the 'multidisciplinary team', comprising student doctors, residents, registrars and senior staff, all of whom have seen everything in our file. The only people who aren't in the know are us!

Often the type of language used in the notes taken about us is influenced by time constraints and convenience. Clinicians may default to language that we consider lazy, formulaised with insulting short-cut language, and repetitive.

Many consumers who have had a chance to see their files, obtained through Freedom of Information legislation, comment on how the vocabulary (the actual words) and the intent (to judge, to criticise, to blame, to understand, to worry, to question, to challenge, to blame) change dramatically with changes in diagnosis. This is especially so when a primary diagnosis is changed from a 'real' mental illness to a 'personality disorder'.

There are other sets of 'illnesses' which seems to promote particularly problematic language (and implied intent) in our records. These include somatoform diagnosis, Munchausen's and related disorders, and eating disorders. There are arguments about why those of us who have attracted these sorts of diagnoses are seen to deserve such dreadful descriptions but there's a feeling that some of it might come out of system-wide helplessness. Clinicians don't know what to do so they blame us.

There are also a number of structural reasons why our records end up being filled with angst and judgment:

- This model of record keeping is derived from physical health and does not translate well into the mental health arena. The observations a clinician makes about our core being, our soul, our person, are not the same as observations about our broken bones or heart valve.
- All the clinical groups tend to reproduce language they learnt in their undergraduate training, and especially in their rotations/rounds/placements in services. Students copy bad practice as well as good practice during these placements.
- Laziness and insecurity are a problem. If a nurse is running late to get his/her obs (observations) finished and ready for handover to the next shift, or unsure of him/herself, there's a strong tendency to paraphrase what was written in the last couple of entries.
- The culture of acute units rarely rewards and sometimes actively discourages whistleblowers who complain about bad practice, including reporting people who write damning and inappropriate things about other human beings. Management and consultants who may try to clean up the act of unimpressive recording-keeping often meet with strong resistance.

## Getting to see your file

The *Freedom of Information (FOI) Act 1982* applies to all public hospitals, community clinics, emergency departments – anything run by the Victorian Government. Information and downloadable forms are available from the Health Department's website (<http://www.health.vic.gov.au/foi.htm>).

The *Freedom of Information Act* does not apply to private hospitals or health providers. However, the *Health Records Act 2001* gives individuals a legally

enforceable right of access to health information about them that is contained in records held in Victoria by the private sector.

This applies to:

- medical practitioners (general practitioners and specialists);
- dentists;
- mental health providers;
- allied health service providers;
- complementary health service providers;
- nursing services;
- private and public hospitals;
- community health centres;
- pharmacists dispensing drugs;
- day procedure centres;
- pathology services;
- supported residential services;
- aged care providers (including nursing homes and hostels, and other service providers);
- disability service providers; and
- palliative care providers.

More information about the *Health Records Act* is on the Department of Human Services website at <http://www.health.vic.gov.au/healthrecords/>.

## Limitations

The *Freedom of Information Act 1982* and the *Health Records Act 2001* both contain clauses which give individual health service providers and institutions the right to delete parts of our file before we access it.

Access can be denied and information can be deleted if it is considered that:

- The information will be detrimental to our mental or physical health;
- A third party will be disadvantaged by release of information that concerns them – this includes other health service providers;
- Another person's privacy is considered to be at risk – this includes the privacy of 'carers' and family members; or
- Release of information may endanger a third party.

## Protecting ourselves when we access our files

Many of us are scared about seeing what has been written about us. Although we may gain strength from seeing the file as proof of our instincts, getting legal 'proof' that we have been discriminated against by a mental health service can be distressing.

Many people ask someone to be with them when they open their file. Sometimes people ask a clinician to go on this journey. What we read in our file can make us angry or upset. Sometimes people who have experienced similar things can help us channel these intense feelings into advocacy or activism or black humour. All of these are terrific ways of healing.

Consumer groups are also useful. It's good to remember we are not alone and, anyway, information from our files gives us great fodder for skits and taking the Mickey out of the mental health system.

## Correcting inaccuracies

Unfortunately, we can't change the information in our files, even if it is inaccurate. There is no legal right to change what has been written about you.

We do, however, have the right to add to our file. This provides an opportunity for some correction of the record; however, be careful and be prepared. Sometimes, in a system where everyone is attuned to detecting pathology, it is possible that attempts to set the record 'right' will be seen as further evidence that we are 'sick', especially if we do it more than once.

## Tips from the experts (consumers!)

Here is some useful information from people who have taken the plunge and studied their files:

- Make sure it's your file! We know of a couple of cases where the wrong person's file has been sent. If it's not yours, imagine what it would be like if the shoe was on the other foot – don't open it.
- Don't read your own history alone unless you are very brave. There may be things in it that really upset you – some of which you may not know about.
- Don't expect everything to be interesting. There will be a lot of boring parts like blood tests and lithium levels and information that we know about already.
- Hospital files used to be hand written and sometimes very hard to read. If you have old files it's interesting to see if you can work out what has been scribbled over by hand and work out why.
- Know what you are looking for. If it's just for interest's sake, you will look at the file differently from someone who is trying to prove a legal case against a service or a clinician.
- Look for patterns and see if they match changes in diagnosis and differing opinions between different clinicians.

Expect some of what you find to be unfair; but if you are so angered by something that you feel action must be taken, your only course is to write something to add to the file. Remember, you can't delete anything.

Consider making additions to the file with the utmost care, particularly if you are going to be using the service again. None of us likes being publicly criticised and there could be a reaction to your attempt to put the facts forward. People see 'the facts' differently. This is especially so in mental health. You can test this theory by looking at material written by medically trained people who nearly always imply that consumer perspective is a 'perception' and medical perspective is a 'fact'.

If you do decide to add something to your file, follow the same rules that apply to writing a letter of complaint:

- Be reasonable
- Don't write when you are angry
- Get someone to check what you have written
- Don't write by hand unless you have to
- Post it in your bottom drawer to set before sending
- Don't use email as it's too easy to prematurely push the 'send' button
- Try to strike a matter-of-fact tone
- Don't use copious exclamation marks, or overuse underlining or capital letters as this is interpreted by some as shouting
- Get a second opinion from friends who have been there and done that.

Ask for both an acknowledgement from the service/clinician that your letter has arrived and a response – within a time frame that is reasonable.

## \* Dealing with Inappropriate Behaviour by Clinicians

**Atrocities in Institutions: noun** All over the world links are being made between institutional 'care' and abuse and trauma. Where are psychiatric hospitals in the scheme of this litigation momentum?

*MadQuarry Dictionary entry 2013*

Terrible things sometimes happen in relationships between clinicians and 'their' patients or clients. Even the use of the possessive pronoun gives away the built-in problem of the power differentiation between clinicians and consumers (often with a layer of gender power thrown in on top).

Really terrible and/or criminal abuse of that power is, thankfully, rare (or, at least, rarely reported).

### Private practice

Consumers don't often talk about their experiences of falling in love with psychiatrists or clinical psychologists, but when you bring a group of consumers together we often do share stories (if reluctantly at first) of quite intimate emotional relationships.

The clinicians have fancy language for all of this but remember, it is their responsibility to resolve, contain, intuit, empathise and own their own part in any miscommunication that takes place. They are responsible for dealing with the situation without causing further harm.

### Naming Names

To know someone's name is to have a degree of influence over your life that you would not otherwise have.

If you are feeling disempowered or vulnerable, ask all students, doctors, nurses, occupational therapists – anyone you come into contact with – to write down their full name the first time you meet.

This will allow you to communicate peer-to-peer. Plus with a full name you are in a much better position to find out information and follow up complaints if need be.

If they don't want to tell you their name, that is up to them (but your message has been sent in any case).

A practicing clinical psychologist or psychiatrist knows that their relationship with those people who trust them sufficiently to share very intimate detail of their lives must never, under any circumstances, develop into something more than a clinical relationship.

Doctors make a Hippocratic Oath, which spells out that which is therapeutic and that which becomes ethically abhorrent. Clinical psychologists are also bound by strict ethics that do not include any sort of inappropriate touching, staring, rearrangement of furniture, sexual advances, or sexualised language or interpretations of their clients' observations.

One of the safety mechanisms in place is an activity called 'supervision'. This recognises that therapeutic relationships are fraught. It's a difficult, often isolated, job. Supervision is mandated in clinical psychology and also used in psychotherapeutic psychiatry. It enables less experienced clinicians to have regular meetings with experienced clinicians on a one-to-one basis. Hopefully through this process many potential boundary violations can be caught before any damage is done.

Some clinicians also choose to meet regularly as a group. This is also an attempt to alleviate the isolating potential of single-person practice.

Despite all the safeguards, unfortunately, sexualised behaviour by clinicians does sometimes happen. This is always totally inappropriate.

### In hospital

It is important to note that physical assault is as inappropriate as any unwanted (or even wanted) sexual behaviour.

Inappropriate behaviours can include (but are not restricted to) forcibly pulling people along, shoving people into seclusion rooms, inappropriate comments or touching, allowing sexual abuse by other patients, overuse of unqualified guards, removing clothing or bedding with force, or sexual assault including sexual penetration.

Some people who have really high or over-excited (what the doctors call 'elevated') moods sometimes behave in ways that are sexualised much more than they would normally but this is no excuse for staff of any kind (psychiatric nurses, occupational therapists, social workers, psychiatrists or clinical psychologists – anyone) abusing their power.

Public psychiatric hospitals can be ugly, unkempt, violent places where nasty things happen to people. The majority of people are there against their will and the angst is palpable. It's a place on a knife edge. Private hospitals can be individualised, rarefied environments where enhanced power differentials are institutionally protected and sometimes less scrutiny of spaces and people occurs.

Within such environments, things can happen and go unreported. Staff can become intimidated and traumatised by other patients and staff. Again, often this is not reported, even when staff know it is happening. Managers of clinical teams may make efforts to support whistleblowers but it doesn't always work.

Even if reported, sometimes clinical misdemeanours are excused. It's not uncommon for patients' reports of assault to be found in their histories as evidence of pathology.

### **What can you do?**

The thing of most importance is your safety and security from the perpetrator. Stay safe. Do what you can to get away from the person who is making you feel unsafe.

If you are feeling up to taking action, there are some other things you can do. As a starting point, it's not a bad idea to keep a business card from the Victorian Mental Illness Awareness Council (VMIAC) on you at all times. You can call them if you are in trouble (phone 03 9380 3900). This is particularly useful for those of us who are on a Community Treatment Order (CTO) or are being case managed by public services.

See 'where to go for help' below for more options.

### **In hospital**

If you are an involuntary patient locked in the same unit in which the perpetrator works, there are some added difficulties. Get away if you can. Certainly contact VMIAC.

If you can't leave, you can try reporting the problem to other staff, particularly clinicians who you like and trust. Good clinicians will protect you, will make sure the complaint is taken seriously and will stand in the way of retribution aimed at you. If you trust them then trust your instincts.

Remember, however, that clinicians are responsible to their team and are obliged (in principal) to report what is said to them. Ask them if they intend to report what you've said to others, to whom, when, and for what purposes.

Keep calm. Try not to get entrenched in the 'squeaky wheel' culture which often prevails in mental health services (whereby the noisiest people get heard at the expense of others). Try to be polite but persistent.

Sometimes this isn't possible. The violation is so great that all we can do is to curl up in a ball and pretend nothing has happened – hiding our terror. This will almost certainly be pathologised but making ourselves feel safer by recreating the foetal position trumps whatever they want to write in our histories.

Others of us will need to act in the opposite way, increasing the escalation of violence. Again if this is the only way we can stay safe so be it. We must survive somehow.

### **Outside hospital**

It can be devastating when misconduct is perpetrated in private rooms, as part of a private clinical relationship, not the least because most of us have loyalty towards our psychiatrist/therapist. In such circumstances we can experience a total destruction of trust.

We are likely to be frightened and confused because this person, who we totally believed was there for us, has shown that they are actually there for him/herself. To walk away from this relationship means we lose the person who is so often the main support in our lives.

Some of us may try to ignore the problem, hoping that everything will go back to normal, but it rarely does. Bullies may use the power differential to make threats; for example, "If you tell then such-and-such will happen."

If you are in this position, it's important that you do not keep this information to yourself. Private patients may wish to contact the Australian Private Consumer and Carer Network (<http://pmha.com.au/pmhccn>), or the Victorian Mental Illness Awareness Council.

See 'where to go for help' below for other options.

### **Where to go for help**

It may feel like it sometimes, but you are not alone!

Below we have outlined some of the places you can go to seek help and/or redress if you have experienced inappropriate behaviour from a clinician.

Different organisations work in different ways and it's worth doing some research before you choose where to go for help. Do you want help getting away? Do you want a clinician struck off the register? Do you want your day in court? Do you want the whole system put under the magnifying glass?

Knowing the answer to the questions above doesn't mean that you'll get what you want, but it does help you clarify who's the best organisation to help or advise you.

Of course, you don't have to do any of these things. We are all individuals and we have the right to follow whatever course (or not) we want. Seek trusted opinions and support, but make up your own mind.

### **VMIAC**

Anyone who has experienced inappropriate behaviour from a mental health clinician (both public and private patients) can contact the peak group for people with mental illness in Victoria, the Victorian Mental Illness Awareness Council (VMIAC – [www.vmiac.org.au/](http://www.vmiac.org.au/)).

VMIAC has a good name amongst consumers for helping us solve all sorts of complicated and personally devastating problems.

VMIAC may be able to link you up with an advocate. The advocate's job is not to do things for you but to be aware of all of the options available to you, as well as the likely consequences of different options.

VMIAC advocates are always consumers themselves, which means you will be able to benefit from their great skill and first-hand experience. A particular result is not guaranteed, but the advocate will be able to walk beside you down whichever path



you choose to follow. They won't push you to make any decision you don't want to make.

### **Complaining to a service**

To make an official complaint directly to a service, you should first find the name of the service (try here: [www.health.vic.gov.au/mentalhealth/services/](http://www.health.vic.gov.au/mentalhealth/services/)).

You then need to find the name of the person responsible for the service and to whom you should address your complaint (often to 'the clinical director'). If it's not clear, you can call and ask to whom a complaint should be addressed. You don't have to provide your name or any details.

See the section below for more on how to make an official complaint.

If you are in hospital and you tell someone about inappropriate behaviour by a clinician, you will generally be directed to make an official complaint. Note, though, that there's no reason why you can't do this at the same time as you are taking other action.

### **The Office of the Chief Psychiatrist**

The chief psychiatrist's responsibilities include monitoring the clinical standards of psychiatric practice and treatment provided by public mental health services, and responding to complaints from consumers, carers and others.

Although Victoria's chief psychiatrist may be employed by the same organisation which employs the staff member you are complaining about, she/he is employed to be (amongst other things) an independent arbitrator (in theory at least).

You can contact the Office of the Chief Psychiatrist by calling 1300 767 299, or by writing to the Chief Psychiatrist, Level 17, 50 Lonsdale Street, Melbourne 3000, Victoria, Australia.

Visit <http://health.vic.gov.au/chiefpsychiatrist/> for more information about the chief psychiatrist's role.

### **The Medical Board of Australia**

The Medical Board of Australia has the obligation to inquire into every complaint of major boundary violation by a doctor.

They get all the information from both sides and then arbitrate on the matter. Consumer observation of the functioning of these Boards is that they may be hard to penetrate over anything that appears to them to be 'minor' but have as much interest as we do in getting rid of doctors who physically or sexually abuse consumers. You may well find that the clinician you are complaining about is already known to them and your complaint will help to make their case watertight.

You can contact the Board by calling 1300 419 495 or via their website: <http://www.medicalboard.gov.au/>

### **Australian Health Practitioners Regulation Agency**

The Australian Health Practitioners Regulation Agency covers compliance issues and non-ethical, non-professional practice across the full range of clinicians who work in mental health, including clinical psychologists, social workers, psychiatric nurses and occupational therapists.

This organisation works in parallel with the Medical Board of Australia and has the same powers but is responsible for non-medical clinicians.

Call 1300 419 495 (ask to speak to a Victorian notifications officer) or visit [www.ahpra.gov.au/](http://www.ahpra.gov.au/) to download a Notification Form.

### **The Health Services Commissioner**

The Health Services Commissioner's priority is conciliation – bringing the two parties together to work out their differences.

This can be a difficult ordeal for some of us. Sitting face to face with the perpetrator may be an experience that would not be good for our mental health.

However, if this is an option you'd like to explore, visit [www.health.vic.gov.au/hsc/](http://www.health.vic.gov.au/hsc/)

### **The Office of the Public Advocate**

The Office of the Public Advocate does not usually play a major role in top-end complaints; if you do contact them they might refer you to other organisations.

However, they do have a complaints mechanism and the Public Advocate does have some powers that may be worth exploring.

### **Community Visitors**

The Office of the Public Advocate also sponsors the Community Visitors scheme in Victoria. This scheme employs people to pay frequent visits to public hospitals, speak to patients and hear complaints which are usually personal in nature.

They have the power to report gross acts of violation straight to the Public Advocate or, with our permission, straight to senior management in the organisation.

Giving permission to the Community Visitor to take our complaint further is something to think seriously about, especially if we are held as an involuntary patient.

Visit [www.publicadvocate.vic.gov.au/](http://www.publicadvocate.vic.gov.au/) to find out more.

### **Professional bodies**

Every association representing a clinical group has an internal mechanism for handling complaints against their members (see the section titled 'Accreditation & Registration' for a listing).

Membership of these organisations is related to registration to practice so they have considerable power, though some consumers believe that they're too "cosy-in-house" (they have an inbuilt loyalty to their members) to be of great use. Nonetheless, none of these associations wants inappropriate behaviour by a member to become public knowledge and they also legitimately don't want rogues amongst their membership.

### **Police, legal action and Community Legal Centres**

It's a crime to assault another person, either physically or sexually, whether it happens in the street or a hospital or in a doctor's consulting rooms.

It is absolutely appropriate to report such behaviour to the police (see a list of contact points here: [www.police.vic.gov.au/content.asp?Document\\_ID=8](http://www.police.vic.gov.au/content.asp?Document_ID=8)). However, some people find this a difficult course to take; for a variety of reasons, including:

- We are scared that because we have a 'mental illness' no one will believe us;
- We are scared that previous episodes of 'illness' might end up coming back to haunt us;
- We are concerned because we still have an allegiance to the clinician concerned;
- We are worried that the medical professionals have so much more power than us;
- We are scared that the whole ordeal will make us sick;
- We don't quite believe that what happened to us was 'real' assault or 'real' sexually inappropriate behaviour;
- We know that because of our low self-esteem we will be easily convinced that it was all our fault;
- We don't know who to trust any more.

It can be a big decision whether or not to take legal action against a clinician. There are many issues to think about. It might be helpful to speak with a VMIAC advocate (see above) or undertake a few sessions with a counsellor to help you think through whether you are happy to take the incident/s into the public arena and to clarify what you want out of litigation.

You may also wish to consult with Victorian Legal Aid (<http://www.legalaid.vic.gov.au/>), which will in most cases provide advice and subsidise our legal costs if a case is to be made. Legal Aid coordinates a network of community legal centres, whose aim is to provide the best possible legal advice to those in our community who have the least resources.

With some research it's possible to find some private firms which have an interest in sexual crime and/or mental health. There could be firms known to the CASA network (see below) that have a sliding scale of fees.

In some (rare) cases, your legal advisers may be interested in running a class action, which means a group of people with similar complaints are brought together by solicitors to put up a joint case which might lead to some welcome wider repercussions.

### **Centre Against Sexual Assault (CASA)**

Regardless of whether we have a mental illness or not, we are entitled to use all the community resources available to any citizen in Victoria.

For inappropriate behaviour of a sexual nature, you can contact CASA (the Centre Against Sexual Assault). Phone 1 800 806 292 or visit [www.casa.org.au/](http://www.casa.org.au/) to find details of local centres around Victoria.

### **Victorian Human Rights Commission**

Another place to consider contacting is the Victorian Human Rights Commission – see <http://www.humanrightscommission.vic.gov.au>.

### **How consumers can help**

We are all different. Nobody can tell anybody else what to do. Even if we have experienced these awful circumstances personally, we can't know what other people will want to do, or be up to doing, or in what time frame.

What we do (or don't do) when these unthinkable things happen is ultimately our choice. There are all sorts of drivers that may stop someone practicing personal safety, or prevent them from seeking justice or retribution. There are many people that prefer to just 'let it go' and many who don't (or can't). We are all individuals and we have the right to do what WE want, unhindered by others – even by others who believe they are 'helping' us.

As consumers, what we can do is be there for our comrades, particularly if they are being accused by the service or clinician of lying, or their distress is being dismissed as being part of their 'mental illness'. We can believe them.

## \* Making a Complaint

**Hospital Complaints:** *noun* Within public hospital settings staff often love us to complain. They might get a new clothes dryer out of it.

*2013 MadQuarry Dictionary entry*

If you feel you have been mistreated by a clinician you may wish to make a complaint.

There are a large number of complaints that people might have, ranging from terrible abuses of trust and power (see previous chapter) through to poor communication and inability to provide a service.

The complaint method we choose to use depends on many things: the relevant complaints body; our need for privacy (and desire to not get 'a name for ourselves'); protection from further abuse; how public we want to be; how many times we've tried before to get our complaint addressed; and what services are available in our geographic area.

Some of the organisations listed in the previous section, particularly the Victorian Mental Illness Awareness Council (VMIAC) and the community legal centres may be able to help you with this.

It can be difficult to write a letter if you don't feel comfortable with your ability to express yourself in writing. But many of us don't want to talk about our complaint with others (this is one reason why many important complaints never get made).

Again, VMIAC or a community legal centre may be able to help those people who struggle with literacy or don't have access to a computer.

### How do I know to whom to complain?

The nature of your complaint will determine where it should be sent. If you are uncertain about which is the appropriate body, read the information in the previous chapter detailing the various organisations involved in dealing with complaints relating to the mental health system.

You may want to contact these bodies before you write anything to seek advice about what to include in your complaint and to whom to direct it. This will give you a feeling for which complaint body is best for your particular complaint. Ask:

- Is this the right body for my complaint? If not, what is? Is there somewhere else should I lodge it as well?
- What is the process for making a complaint? What will happen during the process of the complaint being resolved, and what are the timelines?
- To whom should my complaint be addressed?
- What format does my complaint need to be in (written/verbal/email/

telephone/in person, etc.)?

- If I come to your office in person, can I have an advocate with me?
- Will I need to be in the same room, at any time, with the person about whom I am making the complaint?
- What can I do if I am not happy with the process or the 'resolution'?
- Are there any safeguards to protect my privacy? What are they?
- What does your organisation do to protect me from 'paybacks' within the system?

### Do I need help?

There are complaints and then there are complaints – those that involve serious breaches of trust or criminal acts (assault, rape, physical abuse or injury, for example) almost certainly require that you get some help.

For other less vile but still important complaints, there are many reasons people hesitate to seek help. Some of us are scared that we might be forced under the Mental Health Act to go back into the setting that we fear; some fear other repercussions (e.g. 'payback') could result from the complaint.

Some of us fluctuate between feelings of wanting and then not wanting to complain. This may depend on our nature, our supports, our confidence, our relationship with the clinician involved and the state of our mental and emotional health.

In these situations, our recommendation is to talk to someone from an organisation that makes it their business to help people make complaints. You don't have to go with what they recommend but they will be able to provide support and important knowledge about the complaint process.

Contact the Victorian Mental Illness Awareness Council ([www.vmiac.org.au/](http://www.vmiac.org.au/)) or a community legal centre.

### Some hints about making a complaint

Unfortunately, not all complaints are created equal. How you compose your complaint and to whom you direct it may have some bearing on how it is treated.

Here are some tips from consumers which may help you in framing your complaint.

### Be sure that you actually do want to complain

Consider the pros and cons of making a complaint – is it worth it? If you decide it's not worth it now, write down the details in case you change your mind later.

In making your decision, ask yourself the following (be as honest as you can):

1. Why do I really want to complain? Do I want to change practice for other consumers, or do I want resolution (and/or retribution) for myself?

2. Does the behaviour truly warrant the effort I am about to undertake in making a complaint, or is it more to do with a personal foible, bugbear or crusade?
3. Will my complaint expose any innocent third parties; if so, is this ethical?
4. Will the articulation of the problem actually bring me the release/peace that I so much need?

### **Know how you want the matter resolved**

Sometimes you won't be totally sure but it's important to think about what outcome you want from your complaint. Do you want a clinician struck off the register? Do you want your day in court? Do you want the whole system put under the magnifying glass – a Royal Commission into mental health services? Are you interested in being part of a class action where many consumers with very similar stories of harm come together with the same lawyers, maybe to set a new precedent in common law? Do you want to win a payout for lost income and reputation?

These are all possible outcomes, though in practice they are difficult to achieve. They require funds, lawyers and emotional resilience – all commodities that many of us have in limited supply.

Maybe you wish to have your complaint heard internally within the mental health system, or to get an apology from the clinician concerned and/or the system that employs him/her.

There are many less formal approaches to complaint-making. Getting to know the different options and the different organisations will help you to determine to whom you direct your complaint and it may also dictate some of the content. Often different approaches to making a complaint need different sorts of information in different forms. The more legal the process, the more detailed and sophisticated the information will need to be.

Seek advice – sometimes it's useful to talk to other patients; there is a lot of knowledge out there so don't let it go to waste. There are organisations which can advise you; again, consumer-based organisations such as VMIAC can be particularly helpful.

### **Keep records**

Once you have decided on your preferred course of action (and, in fact, before that if possible), start keeping records. The more detailed and accurate your records are the better.

Take notes at meetings, note the dates, write down who was present, what was said, any undertakings that were made, and what the next steps are going to be. If you need to concentrate on speaking, co-opt a scribe to do the writing.

### **Do it in writing**

A written complaint will often be more effective than a verbal one – it's set in stone (no one can dispute what you said), and it's harder to ignore.

A typed complaint may be better than a written one (if only because it cuts out the drama of someone having to read your handwriting). If you're in hospital, that might mean that you have to wait until you've been discharged and can get access to a computer.

If you do decide to submit a hand-written complaint, don't underline, don't use capitals, don't use too many exclamation marks, don't use red ink, and try to keep to all the principles of clear communication outlined below.

Be wary of using email. It can be viewed as informal and, like a verbal complaint, it can be easy to ignore. It's also a format that allows easy sharing of your (probably) very personal information among too many people. Emails are prone to being sent hastily, and before you've really thought through what you want to say.

### **Pay attention to your writing**

If you don't have confidence in your written communication skills ask someone to help or to check or edit what you have written before you put it in the post.

Here are some of the things you may wish to pay attention to when composing a written complaint.

- Be brief – try to state your points clearly, but succinctly (and once only). Use headings and dot points if they help you get your points across more clearly.
- Use a tone that expresses confidence that the matter can be dealt with and that you expect it to be dealt with. It's sometimes useful to conclude with an expectation of the action you expect in response – perhaps a formal reply addressing all the points you have raised in your letter.
- Keep it formal – your complaint should be viewed as an official record so you should address people with their titles.
- Try and keep your language clear and under control. Blatant (or even righteous) anger is a turn off for many people and unfortunately can be seen as a symptom of our 'illness'.
- Don't swear or use overly inflammatory language. Try to avoid ultimatums (at least in the first instance).
- Don't exaggerate or make unfounded accusations – the complainant will be only too happy to pick errors in your account of events.
- Tone down your punctuation – don't use red ink, capital letters, underlining or too many exclamations. These can be interpreted as symptoms of your 'illness' and used as an excuse to take your complaint less seriously.
- Don't compromise – make an effort to sound reasonable but don't say what

you don't mean and don't apologise for things you're not apologetic about.

- If you have a tendency to act in haste (and regret at leisure), finish your complaint then file it in the bottom drawer for a day or two before you post it.

## Open letters

An open letter is a letter designed for public consumption that you submit to newspapers, journals, newsletters or, perhaps, Facebook or the digital media (a blog, say) in general.

Some people also write an open letter to health ministers in state and territory governments, CEOs of non-government organisations, or directors of mental health departments.

Think carefully about doing this – are you really ready for your story to be in the public domain? Once the genie is out of the bottle it will be impossible to put it back in.

If you do go down this route, think carefully about how you sign off.

For letters to the editor, it is not always necessary to use your name; even those that do require a name will often allow us to have our name withheld from public view ('name supplied but withheld'). However, bear in mind that this may have the effect of perpetuating the view that 'mental illness' is something to be kept hidden at all costs.

Similarly, try not to sign an open letter with just a first name (Susan, Michael, Ahmed). This just reinforces the community perception that it's OK to treat people with 'mental illness' like children. If you want, perhaps you can use a pseudonym – a fake name but a full name.

Finally, consider seeking a legal opinion before you submit a letter designed for public consumption. It may be necessary to de-identify details such as the name of the hospital or the name of the clinician to protect yourself from being sued (or worse). The last thing we need is to end up in court charged with defamation.

## The reality

Once you've started along the road of making a complaint, try to remain hopeful but realistic – unfortunately, few complaints in this area are resolved in a way that the complainant finds totally satisfactory.

Prejudice against people diagnosed with mental illness is rife and even bodies that are set up to protect the rights of patients sometimes start from the assumption that our thinking, our reality, our memories, our version of the story are more likely to be flawed because of the nature of the 'illness'.

Medicine is a powerful institution. It can be difficult to take it on. Complaints processes can be particularly hard ordeals for people with stress related 'illnesses'.

You may also come up against a phenomenon called 'closing ranks', whereby people tend to defend their colleagues as a matter of course, no matter what. (On the other

hand, there are sometimes 'whistleblowers' who might appear out of the blue to support a complaint from a consumer.)

Issues of power may come to the fore. The organisation involved in the complaint will probably have access to your file. They may pathologise your complaint. They may feel the need to consult many people about the incident. They can stretch out this process for a long time and still come back with a reply you find unacceptable.

Don't forget that there are other processes, other organisations and other people to whom you can now turn if your complaint is rejected.

Of course, many (most?) people dealing with complaints are genuinely interested and concerned. You may well get a good response. When this happens, it's a good idea to let them know you are grateful – it will help smooth the path ahead for others.

## Other resources

Here are some other useful resources on making a complaint:

- *Making a Complaint in Psychiatry* by Loane Skene, Fitzroy Legal Centre: <http://www.lawhandbook.org.au/handbook/ch19s01s07.php>
- How to make complaints about people within the system who are not clinicians: [http://www.health.vic.gov.au/mentalhealth/archive/patientrights/major\\_non-psychiatric\\_treatment.htm](http://www.health.vic.gov.au/mentalhealth/archive/patientrights/major_non-psychiatric_treatment.htm)
- *Patients' Rights: A self-help guide to Victoria's Mental Health Act*: [http://www.communitylaw.org.au/mentalhealth/cb\\_pages/images/patients\\_rights.pdf](http://www.communitylaw.org.au/mentalhealth/cb_pages/images/patients_rights.pdf)

## \* Saying Thank You to a Clinician

**Everyone-needs-some-appreciation Syndrome: A group of symptoms that indicate that human beings all need appreciation of our efforts no matter who we are.**

*2013 MadQuarry Dictionary entry*

Many consumers ask us if it's OK to write a complimentary letter or give their psychiatrist a photo or present for Christmas with a thank you card.

People's diffidence arises for two reasons. Firstly, many of us are confused about the idea of boundaries and what this does or doesn't allow us to do.

Secondly, letters of thanks are rare in psychiatry – psychiatry is not obstetrics; both clinicians and consumers are much more used to complaints than they are compliments, especially in the public sector.



## Boundaries

The issue of 'boundaries' presents a confusing dilemma for many consumers. The theory is straightforward enough: clinicians have an obligation to manage the therapeutic relationship in such a way that their patients/clients will remain emotionally and physically safe. They are required to manage all interactions to keep an emotional and physical line between themselves and us.

In reality, though, in some situations the relationship does become (and needs to become) quite intimate. The problem is, without due diligence these intimate relationships can turn into the wrong type of intimate relationship which will hurt us more than anything else and ruin any therapeutic value.

On the other hand, many consumers believe that 'boundaries' are often used by clinicians to control people, or as an excuse for poor communication.

Just as some clinicians seem all over the place in how they define appropriate 'boundaries', consumers' need for closeness and distance also vary enormously.

In private psychiatry these confusions can be worked through over time but in the come-and-go world of public psychiatry this is rarely a possibility. The most likely scenario is that consumers are being told that they need to keep proper boundaries without ever knowing what this means.

Saying thank you for the receipt of good practice is not in and of itself too intimate in relation to 'appropriate' consumer/clinician relations. However, some clinicians providing some sorts of therapeutic interventions will not accept anything and will refuse our gestures of kindness. These will probably only be clinicians working with a particular form of psychotherapy/psychoanalysis.

If you are concerned about what the reaction to an act of gratitude might be, maybe ask them first.

## A shortlist of what it is OK to do (and not so OK)



### Thank you letter

It's fine to write a thank you letter to any clinician. If the person is a clinician in a hospital setting, you may not even know their name but give it a try anyway. Contact the hospital or unit and see if you can find out. They will get a real buzz out of receiving a thank you note out of the blue. Don't expect them to remember your name (or reply), just feel pleased at the pleasure they'll get from being appreciated.



### Christmas/Celebration card/gift

Sending or giving a clinician a card for Christmas with some words of appreciation is a nice gesture. Marking other Jewish, Buddhist or Muslim days of celebration is also fine.



### Thank you note to a private clinician

If you see a clinician regularly, a note of thanks at any time should be fine, provided it does not contain too much familiarity (this might worry the clinician). If you are not sure what they might perceive as "too familiar" maybe hold off until you have been seeing them for longer and have a better idea about their view of 'boundaries'.



### Thank you note to a Unit Manager

Writing a letter to a clinician who is working as Unit Manager to thank him/ her for the good things that happened during your stay is a lovely gesture. Provide detail of what/who was good if you can; it will promote better practice. Again, don't expect a reply.



### Thanking hospital staff in person

When you are in hospital you may sometimes feel like you want to show some sort of appreciation with a gift for staff who are still involved with your care. This ground is a bit trickier for myriad reasons. For example, it can be misconstrued as over-familiarity (crossing 'boundaries'); it can make life tricky for junior staff who might be seen by more experienced clinicians as not maintaining appropriate 'boundaries'; or it may be seen as an attempt at 'bribery' or currying favour. By all means, find out the staff members' names if you can so you can write to them later.



### Sending flowers/chocolates/gifts

Flowers are interesting. In a general medical setting, chocolates and flowers are often given when people leave mainstream hospitals, but such traditions are virtually non-existent in psychiatry. The nature of psychiatry, especially where people are held against their will, seems to be flower-phobic, both for inpatients and for staff. It is OK to challenge these assumptions if there has been what you consider to be special care in a horrible place. A short, appreciative card or a small posy of flowers from the garden may help lift some lagging spirits.

## Constructing a written message

In most instances, it's best if your words of thanks are expressed on a card. For one thing, it stops us from slipping into 'overdoing it' mode!

The exception to this rule is where you are writing to a unit manager or some other person where you want to reinforce good practice. In these cases, it can be useful to include dot points of all the things that you found to be good. (It is OK in such a letter to include a couple of practices that could be improved so long as the positive largely outweighs the negative.)

Because consumer-clinician relationships can be one-sided, power-based, tricky, and in some ways unknown, it's best to keep your words short, meaningful, individualised and genuine. Try to maintain your status as a 'patient'.

A couple of words of warning: in all cards and letters, we must be vigilant about confidentiality, especially third-party confidentiality. And keep a copy of all correspondence, just to be safe.

## \* Privacy, Secrecy and Confidentiality

**Confidentiality: noun** Communication and confidentiality need to be friends not enemies.

*2013 MadQuarry Dictionary entry*

Issues of privacy, secrecy and confidentiality are often uppermost in our minds after we are diagnosed with 'mental illness'.

There are differences between these three concepts as we generally understand them. Our commonsense understanding suggests that:

- **Confidentiality** refers to information that is written about us and words that are spoken about us within a medical context;
- **Privacy** means the sanctity of our bodies and other aspects of our lives that might have nothing to do with our mental health. This includes our right to live our lives free from unwanted intrusion from the State and individuals we choose not to include.
- **Secrecy**, on the other hand, has slightly sinister connotations. This can be when we are kept in the dark even about things that intimately affect us. Secrecy, in a mental health context can also refer to others' efforts to hide us because we carry the mark of disgrace – the stigmata (sign) of 'mental illness'.

Even amongst ourselves, consumers have widely differing ideas about these three concepts. What is experienced by one person as 'necessary privacy' may be for another 'dangerous secrecy'. Personalities and our past histories influence our views.

## The family context

One of the contexts in which these competing ideas can be most problematic is in the relationship between us and our families. Sometimes our families try to 'shut us up'. They seem to be convinced that even though we seem to freely talk about our experiences of 'mental illness' we don't really want to disclose so much to the world. Behind them stands a mountain of 'evidence' that we might not be very good decision makers about such things, especially when we are 'unwell'. This can cause conflict.

There is an element of truth on both sides. At times families are understandably embarrassed. This is the nature of cultural censure. Instead of facing this embarrassment and coming to terms with the social pressures that are driving their feelings, they sometimes blame us, especially when we refuse to be silent. As people diagnosed with 'mental illness', we can be sitting ducks for this sort of displacement behaviour.

On the other hand, some of our experiences of mental distress leave us prone to over-analysis which, when verbalised to others, can be experienced as both too divulging and also boring.

## Expectations

There are also problems in relation to what we sometimes believe we are expected to divulge to those with whom we have an ongoing therapeutic relationship. This is largely to do with differences in power between us and our psychiatrists, psychologists, nurses, counsellors or other clinicians.

As clinical psychologist and consumer Patricia Deegan puts so well, "A meeting with a psychiatrist need not be a confession!" <https://www.patdeegan.com/pat-deegan/publications/all-papers>

## Confidential(ish)

There are ethical and professional responsibilities of clinicians in relation to privacy and confidentiality.

Medical professionals are required by the standards of their professional organisations, their registration bodies and their employing organisations to respect the confidentiality and privacy of the people they treat. Most medical professionals practicing in the field of psychiatry believe they do this. They would be dismayed that many of us are so critical of their practice in relation to confidentiality.

Our criticism tends to hinge on the fact that they do not treat other medically trained people the same way as they treat lay people in relation to confidentiality. That is, information that is not necessarily relevant is routinely passed from one doctor to the next, from one nurse in casualty to another nurse in the hospital – and to other clinicians who do not need to know.

We believe that this is bad practice. 'Mental illness' is not like other illnesses. It

is maligned and misunderstood – even by many medical people. The starting assumption should always be that the only people who should be privy to information about us are those who need to know for the ‘treatment’ to be carried out in the best way possible.

It is imperative that everyone being treated for ‘mental illness’ – especially in an inpatient situation – knows that when a staff member says, “this is confidential” they mean, “confidential to the team”. That is, the information can be passed to other people who are deemed to be part of ‘your’ treatment ‘team’.

Many inpatients are unaware of this and believe that when they reveal really private and important things – even disclosure of childhood abuse – these revelations will go no further than the person they have learnt to trust and to whom they have actually spoken. The reality is that this person is in no position to promise this sort of confidentiality. They are required as part of their responsibility as a ‘treating team’ member to not only pass on this information verbally but also to document it in the patient’s file.

Often, there is no transparency around this expectation. Ideally, clinicians should tell us all of this when we are first admitted to the ward or unit in order to allow us to make an informed decision about what we will divulge and to whom. However, this is rarely done.

### **The cloak of ‘confidentiality’**

Often it feels like everyone seems know what is going on (about us) except us. No one tell us anything.

At the same time, those we **want** clinicians to talk to are shut out under a cloak of ‘confidentiality’. We believe this is lazy communication. Confidentiality should not be used as an excuse for poor communication. It is our lives. We should be able to ask clinicians to speak to whoever is important to us. This will not always be the people whom the service recognises as ‘next of kin’ or ‘carer’ – it could be a lover, a priest, or simply a close and trusted friend.

Many of us now use an Advance Directive to allow us to indicate, as officially as possible, to whom we want clinicians to talk, and what we want to be kept private.

### **Legal protection**

In Victoria our privacy is, on paper, protected by both state and federal legislation. The pertinent Acts are:

- *The Information Privacy Act 2000*, which covers state government agencies and local councils, and includes 10 Information Privacy Principles. See [http://www.austlii.edu.au/au/legis/vic/consol\\_act/ipa2000231/](http://www.austlii.edu.au/au/legis/vic/consol_act/ipa2000231/).
- *The Freedom of Information Act 1982* ([http://www.austlii.edu.au/au/legis/cth/consol\\_act/foia1982222/](http://www.austlii.edu.au/au/legis/cth/consol_act/foia1982222/)) and the *Public Records Act 1973* ([http://www.austlii.edu.au/au/legis/vic/consol\\_act/pral973153/](http://www.austlii.edu.au/au/legis/vic/consol_act/pral973153/)), which govern access to public record

- *The Privacy Act 1988* ([http://www.austlii.edu.au/au/legis/cth/consol\\_act/pa1988108/](http://www.austlii.edu.au/au/legis/cth/consol_act/pa1988108/)), which covers federal government agencies and parts of the private sector.
- *Victoria’s Health Records Act 2001* (<http://health.vic.gov.au/healthrecords/>), which covers health information in Victorian public and private sectors from July 1, 2002.

See the *Community Law Handbook’s* arguments about the difference between confidentiality and privacy and how this might affect any actions we might consider taking – both legal and non-legal:

<http://www.lawhandbook.org.au/handbook/ch19s01s04.php>

# APPENDIX

## A Note to Clinicians

### Hey you! Yeah you – the new worker ready to change the world and fix some lives, welcome!

We hope your stay as a psych worker is a long and productive one. Here are some hints that may help you do the most good and the least damage along the way.

1. A diagnosis tells you nothing about the person. It tells you their diagnosis, which, if correct, can act as a map to best helping them, but too often it is used as a cage to trap people in. Our diagnosis doesn't tell you anything about our self of humour, or our political leanings. It tells you nothing of our aspirations or achievements, physical health, food preferences or about how we might pick our toenails when nobody is looking. But all of these things go to make up who we are. They're just as important – *way more* important – than a diagnosis. A diagnosis is just a map on one page of the huge atlas of us, and the map may well be faulty.
2. You may well be seeing us at the very worst time of our lives. Remember that always.
3. "Nothing about us without us" – include us in our own care as much as possible, using language we can understand and in whatever ways we are best able to communicate.
4. Don't be afraid of connection, it can be the most healing power of all. Knowing that you also love gardening or cooking or Lego, discussing those things with us, can help us feel much less estranged from the world.
5. Psych. services can be really scary places full of scary and scared people. Never assume that just because we are one of them that we are comfortable in the situation. Would you be?
6. We have lives when we are not in your care, stuff outside needs to be taken care of, bills need to be paid, the cat needs to be fed and the kids need their noses wiped. Telling us to not worry about that stuff doesn't make it so. Even if you can't fix anything, letting us talk about the frustration and fear and helping us to work that stuff out can be as healing as any medication regime. Hospitalisation is a huge, stressful event in any life, let alone adding in an illness that may be changing your thoughts and attitudes, emotions and reactions.
7. Accept that the file is written by flawed human beings who may have got things wrong. Think about how often in your life you have been misinterpreted – now, imagine if what you said was written down and all that followed was based on it. Make sure you write down what we think is important for people to know, even if you don't see the relevance. Knowing we are heard is really important, you don't have to agree with it to record it.
8. Don't assume that we automatically want to look and live like what you consider to be 'normal'. That may never work for us, we may not want it and even if it is possible the costs may be astronomical. Work with us to find out what 'well' looks and feels like for us. That should be our collective aim.
9. I'm sorry to break the news but no matter how wonderful you are, no matter how politically sound you are, no matter how lofty your intentions ... if you can hold us against our will, medicate us, write things in a file we can't read and make decisions about our lives we will never have an equal partnership, ever. It can't happen. We can be partners, we can collaborate, but it takes extra effort from you to recognise that you still hold power. If you hate that idea, get out now. If you like it a lot, please get out now. Just don't pretend otherwise, we know the score.
10. Finally, please look after you – we need good workers. Maximise your leisure time, laugh at the funny stuff, and always remember that we have more in common as human beings than any differences that so-called illnesses create. You can have bad days (but please try to let us know that it isn't our fault). Remember we can have bad days too. Good luck.

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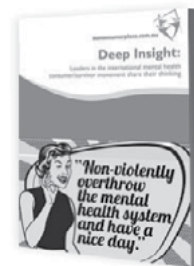
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